EPIDEMIOLOGY OF VOICE AND SWALLOWING DISORDERS IN RHEUMATOID ARTHRITIS

by

Charisse E. Wright

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STATEMENT OF THESIS APPROVAL

The thesis of _____Charisse E. Wright_____

has been approved by the following supervisory committee members:

_____Nelson Roy_____, Chair	4/22/2014	Date Approved
_____Michael Blomgren_____, Member	4/22/2014	Date Approved
_____Bruce Smith_____, Member	4/22/2014	Date Approved

and by _____Michael Blomgren_____,

Chair of the Department of Communication Sciences and Disorders,

and by David B. Kieda, Dean of The Graduate School.

ABSTRACT

Rheumatoid Arthritis (RA) is an autoimmune disease that causes inflammation of the joints and organs that may produce voice and swallowing disorders. However, little is known regarding the true prevalence of voice and swallowing disorders in RA. This epidemiological investigation examined questionnaire responses from 100 individuals with RA to determine the frequency, severity, risks associated with, and socioemotional impact of voice and swallowing disorders in RA. Detailed medical, psychosocial, occupational, and lifestyle histories, as well as health, voice, and swallowing-related quality-of-life instruments were also included. The results were analyzed using summary statistics, frequencies, chi square tests, risk ratios, and associated confidence intervals ($p < 0.05$). The prevalence of a current voice disorder was 35%. The majority of these voice disorders began gradually (82.9%), and were chronic (85.7% persisting for more than 4 weeks). Forty-one percent of participants reported a current swallowing disorder, which began gradually (90.2%) and was chronic (82.9%). The most common voice symptoms included frequent throat-clearing, chronic throat dryness, hoarseness, and loss of singing range. Voice disorders were more common in those with sleep disorder, tension in the neck/throat or jaw, among those who were quiet, and among those who were physically inactive. The prevalence of a current voice disorder did not significantly differ across the levels of age, sex, severity of RA, race/ethnicity, income, or education. The most common swallowing symptoms included dry mouth, difficulty swallowing

solids, coughing frequently during meals, needing to take smaller bites to swallow safely, and foods sticking in the throat. Risk factors for swallowing problems included thyroid problems, esophageal reflux, tension in shoulders or abdomen, experiencing voice problems with a job, and being physically inactive. Both voice and swallowing problems produced adverse effects on quality of life. These results indicate that voice and swallowing disorders are relatively common in RA. These results have important implications for the recognition and treatment of voice and swallowing disorders in this population.

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INTRODUCTION

From the beginning of life, the capacity for oral communication and swallowing are central to human health and well-being. These behaviors—both with commonalities in shared anatomy and physiology—may be adversely affected by disease processes. These diseases may result in the loss of two behavioral sets that are central to the human experience, voice and swallowing. In this regard**,** autoimmune diseases are associated with the body's inappropriate defense against its own healthy tissue and, consequently, may affect voice and swallowing function. Rheumatoid Arthritis (RA) is one such disease. This study aimed to examine the epidemiology of voice and swallowing disorders in individuals with RA.

Rheumatoid Arthritis

RA is a disabling autoimmune disease characterized by synovitis, or inflammation of the synovial tissue of the joints, which may be followed by periods of remission when no synovitis is present. Joints most commonly affected by RA include hands, feet, ankles, and wrists, although any joint may be involved (Davis & Matteson, 2012); this includes joints in the larynx (Tamowska et al., 2004). Manifestations of RA in the larynx may cause problems with swallowing and the voice (Berjawi et al., 2010; Fisher, Dolan, Hastings, McClinton, & Taylor, 2008; Liu, Masterson, Srouji, Musonda, & Scott, 2012;

Ruiz Allec et al., 2011; Speyer, Speyer, & Heijnen, 2008; Woo, Mendelsohn, & Humphrey, 1995).

RA is diagnosed based on the presence of at least four of the following symptoms: morning joint stiffness, arthritis of three or more joint areas, arthritis of hand joints, symmetric arthritis, rheumatoid nodules, and radiographic changes (Arnett et al., 1988; Davis & Matteson, 2012). Rheumatoid Factor (RF), which is an autoimmune antibody, is also a marker for RA, although it may be present due to other conditions as well. Typically, however, approximately 80% of individuals with RA will have elevated RF levels. RF is a predictor of poor prognosis and is measured in units called titres. When titre levels are higher, individuals are more likely to experience joint erosion and consequently greater disability. When RF deposits in tissue, it results in the formation of rheumatoid nodules (Wilson, 2006). Another marker of RA is the detection of antibodies directed to citrullinated peptides or proteins, as measured by an anti-cyclic citrullinated peptide test. This test is more specific than the RF test and has comparable sensitivity (van Venrooij, van Beers, & Pruijn, 2008). Both of these tests are recommended when initially diagnosing RA.

Although the etiology is unclear, RA affects approximately 1% of the worldwide population, and 2 to 3% of the adult population (Helmick et al., 2008; Woo et al., 1995). The average age of onset is 55 years old, but RA has been diagnosed in individuals as young as 2 years old. The prevalence of the disease increases with age, as it has been reported that 6% of the population of White adults over age 65 have RA. Women are more than twice as likely to develop RA than men (Davis & Matteson, 2012).

Laryngeal symptoms of RA include bamboo nodes, dysphonia, dysphagia, and

stridor. Rheumatoid, or "bamboo," nodules are yellow midmembranous vocal fold swellings that have a calloused appearance, and may occur in as many as 25% of individuals with RA (Mikkelsen & Duff, 1955; Webb & Payne, 1972; Woo et al., 1995). In addition to these laryngeal changes, many individuals with RA have reported difficulty swallowing (i.e., dysphagia), the feeling of a foreign body in the throat, pain with speaking, vocal fatigue, stridor or breathing difficulty, and other swallowing symptoms (Jacobs & Hui, 1977; Tamowska et al., 2004; Vergnenegre et al., 1997). Stridor reportedly occurs in RA due to fixation of the vocal folds via the cricoarytenoid joint (Erb, Pace, Delamere, & Kitas, 2001; Tamowska et al., 2004). Upper airway obstruction may occur in up to 16% of individuals with RA (Vergnenegre et al., 1997). However, Gomez-Puerta et al. (2013) reported no cricoarytenoid joint involvement in any of the 36 participants with RA involved in their study. The authors did observe symptoms of pharyngeal-laryngeal reflux in 64% of participants.

Conflicting reports exist regarding the prevalence of laryngeal abnormalities in RA. Some studies have reported a very high frequency of laryngeal changes, up to 80%, in participants with RA (Abadir & Forster, 1974; Bienenstock, Ehrlich, & Freyburg, 1963). In contrast, Lofgren and Montgomery (1962) reported laryngeal involvement in 26% of participants with RA based on patient histories, extralaryngeal palpation, and indirect laryngoscopy. Another study used indirect laryngoscopy and computerized tomography, documenting laryngeal manifestations in 32% and 54% of participants, respectively (Lawry et al., 1984). A third study used the Voice Handicap Index (Jacobson et al., 1997) and a three-item outcome scale to determine prevalence of laryngeal involvement in RA. Questions included smoking habits and information of the

participant's profession. This study found the prevalence of voice problems in RA to be 12 to 27% (Speyer et al., 2008). Beirith, Ikino, and Pereira (2013) found laryngeal disorders in 72.4% of RA participants, with a 12.8% prevalence of dysphonia. This study recruited 87 participants total, 47 of whom had RA, compared to a control group of 40 participants. The presence of RA was evaluated based on disease activity score (DAS-28), and the presence of laryngeal disorders was determined based on laryngeal symptoms, the Voice Handicap Index, and laryngoscopy findings.

By comparison, the current and lifetime prevalence of voice disorders in the general adult population are 6.6% and 29.9%, respectively, and are strongly associated with sex, age, voice use patterns and demands, esophageal reflux, chemical exposures, and frequent cold or sinus infections (Roy, Merrill, Gray, & Smith, 2005). The prevalence of voice problems in the RA population is expected to be higher than the general population as additional factors, such as rheumatoid nodules, cricoarytenoid joint arthritis, esophageal reflux, and other conditions might increase likelihood of these problems. The severity of the autoimmune disorder might also be a contributing factor.

In a similar vein, it has been reported that 12 to 13% of adults in the general population have a current swallowing disorder (Groher & Bukatman, 1986). Risk factors for swallowing problems include aging, stroke, and other neurological conditions such as Parkinson's Disease. Cricoarytenoid joint arthritis and rheumatoid nodules may affect swallowing, increasing the prevalence of swallowing problems in the RA population (Abadir & Forster, 1974; Bienenstock et al., 1963). For example, arthritis was identified as a risk factor for swallowing disorders in an epidemiological study of dysphagia in the elderly (Roy, Stemple, Merrill, & Thomas, 2007).

While voice and swallowing problems have been reported in the RA literature, few studies have been conducted to determine the true prevalence of these problems. Those studies that have been conducted have reported conflicting results. Furthermore, few studies have examined possible risk factors, and/or the adverse socioemotional effects of such voice and swallowing disorders when present. Table 1 summarizes and critiques studies of laryngeal involvement in RA.

Inspection of Table 1 reveals that there is considerable variability in the results of studies analyzing the prevalence of laryngeal involvement and various voice and swallowing symptoms in RA. Because of these discrepancies and the lack of research in this area, further study is necessary to determine the true prevalence of voice and swallowing disorders in RA. Additionally, it is important to determine the medical and health history factors, occupational history factors, lifestyle factors, and voice and swallowing symptoms that are associated with RA. While it is clear that RA has a significant impact on an individual's health and well-being, little is known regarding: (1) the prevalence of voice and swallowing disorders in RA, (2) patterns/symptoms of voice and swallowing disorders in RA, (3) risk factors associated with these disorders, and (4) consequences of voice and swallowing disorders on social and emotional functioning in the RA population.

Purpose

Epidemiology is the study of the relationships of various factors determining the frequency and distribution of diseases and disorders in a population. At present, the true prevalence of voice and swallowing disorders in RA is undetermined. This descriptive,

Table 1. Characteristics of studies examining voice and swallowing dysfunction in RA

Study	# of Partici-pants	Gender Representa-tion	Age	Method	Findings	Weaknesses/ Limitations
"Prevalence and Relative Risk of Dysphonia in Rheumatoid Arthritis" Speyer et al., 2008	166 RA 148 control	47 men, 119 women	19-89 years, average age = 61	Visual analog scale of severity by rheumatologist and patient; VHI and three-item outcome scale on perception of impairment	Prevalence of 19% found in RA participants, compared to 6% in controls. RA 2.9-3.7 times more likely to have dysphonia	72% women in patient group vs. 52% in control group; mean age in participants = 61 vs. 54 in control group; Limited items on VHI and 3-item outcome scale; No accounting for habits, medical history, etc.
"Rheumatoid nodules of the larynx" Woo et al., 1995	64-year-old female	1 female with RA	64	Flexible laryngoscopic examination; laryngostroboscopy to assess vibratory function; microdirect laryngoscopy; evacuation of subcordal masses from each vocal fold	Rheumatoid nodules can affect the vocal folds, which causes hoarseness or dysphonia; RA in the larynx is found in as many as 25% of RA participants	Single subject with RA rather than wide-scale representation; no quality of life measures
"Incidence of Laryngeal Involvement in Rheumatoid Arthritis" Lofgren & Montgomery, 1962	100 participants with RA	68 females, 32 males	N/A	External palpation and indirect laryngoscopy	26% of RA participants examined were found to have involvement of cricoarytenoid joint	Few questions (8), information on age of participants not disclosed, no information on extent to which quality of life was affected
"Prevalence of subjective voice impairment in rheumatoid arthritis" Fisher et al., 2008	73 with RA 73 controls	N/A	N/A	VHI-10 and Reflux Symptom Index to assess symptomatology of laryngopharyngeal reflux; Participants with RA had a joint assessment, erythrocyte sedimentation rate (ESR) and visual analog to calculate Disease Activity Score (DAS)	Findings suggest a prevalence of subjective voice impairment of 5%	This study did not assess fatigue or depression, which may affect subjective voice impairment; Larger study needed to determine relationship between disease severity and higher VHI scores
"Voice Symptoms in Patients with Autoimmune Disease: A Cross-sectional Epidemiological Study" Liu et al., 2012	109 participants with auto-immune disease (60% with RA) 41 controls	74 women and 35 men in autoimmune group	Average age similar for autoim mune and control groups	VHI-10, xerostomia scale, acid reflux inquiry, and anxiety/depression scale	16.6% of autoimmune group reported significant voice symptoms	Further study necessary to determine possible cause of increased prevalence of voice disorders; Participants were not limited to those with RA
"Cricoarytenoid Joint Abnormalities in Patients with Rheumatoid Arthritis" Berjawi et al., 2010	11 participants with RA 8 controls	2 males 9 females in RA group	22-65; mean age 48.5 years	Laryngoscopic evaluation, acoustic analysis, computerized tomography; Hoarseness, loss of range, vocal fatigue were vocal symptoms inquired	Almost 2/3s of RA participants had loss of range, and 66% had hoarseness compared with 25% in control group; 9.1% had decrease in vocal fold mobility and 27% had moderate/severe edema of vocal folds/arytenoids compared with none in control group	Few participants recruited; no measures on quality of life, or medical, professional and current voice use, etc. Measures used only to evaluate current symptoms

Table 1. Continued

Study	# of Partici-pants	Gender Representa-tion	Age	Method	Findings	Weaknesses/ Limitations
"Hoarseness Due to Bamboo Nodes in Patients with Autoimmune Diseases: A Review of Literature" Hilgert, Toleti, Kruger, & Nejedlo, 2008	3 female participants with bamboo nodes	3 females	29, 31 and 50	Endoscopic laryngoscopy and laryngostroboscopy and phonetogram documentation for logopedic voice investigation	Bamboo joint-like nodes were identified in 3 female participants	Only 3 participants; no information on risk or protective factors or prevalence
"Swallowing Problems in Rheumatoid Arthritis" Geterud et al., 1991	29 RA 30 controls	All females	41-69	Questionnaire, physical examination, stimulated saliva secretion, labial salivary gland biopsy, esophageal manometry, and laboratory blood tests	Dysphagia was experienced by 8 patients (28%) compared with 1 control subject and was associated with disease severity; 69% of participants had laryngeal involvement	This study did not separate RA participants with and without Sjogren's syndrome, which significantly affects results
"Arytenoid adduction to treat impaired adduction of the vocal fold due to rheumatoid arthritis" Kumai, Murakami, Masuda, & Yumoto, 2007	1 female with RA	1 female	57-year old with 10-year history of RA	Arytenoid adduction surgery performed to normalize voice	In cases of bilateral cricoarytenoid joint involvement in RA, airway obstruction can occur	Only 1 subject reported; no information on prevalence of airway obstruction due to RA
"Airway obstruction and rheumatoid arthritis" Vergnenegre et al., 1997	100 participants with RA, 88 participants with other rheumato-logical diseases	77 females, 23 males in RA group; 67 females, 21 males in control group	RA group = 60+/- 12 Control group = 57 +/- 21	Questionnaire, spirographic measurements taken, chest radiograph	Number of obstructive syndromes was higher in participants with RA than other rheumatologic conditions	This study used both subjective and objective measures but only measured respiratory problems rather than voice and swallowing problems - which may be related
"Laryngeal assessment by videolaryngeal-strooscopy in patients with rheumatoid arthritis" Gomez-Puerta et al., 2013	36 participants with RA	33 females, 3 males	56;3 +/- 14;2 years	Reflux Symptom Index (RSI), Voice Handicap Index-10 (VHI -10) to evaluate vocal cord impairment, videolaryngostrobo-scopy to determine laryngeal involvement	Organic involvement was uncommon, 1 patient had bamboo nodules, no cricoarytenoid impairment was found, but pharyngeal-laryngeal reflux was found in 64% of participants	Relatively small number of participants with RA; evaluated laryngeal involvement with stroboscopy but did not assess swallowing
"Laryngeal involvement in rheumatoid arthritis" Beirith, Ikino, Pereira, 2013	47 participants with RA, 40 controls	40 females, 7 males in RA group 26 females, 14 males in control group	RA group = 56.5 +/- 12.6 years 47.9 +/- 13.6 in control group	Evaluated participants with RA according to disease activity score, laryngeal symptoms, VHI, and video-laryngoscopy compared with a control group	Prevalence of dysphonia was 12.8% and videolaryngoscopy changes 72.4% in participants with RA; Posterior laryngitis was the most common diagnosis	Relatively small number of RA participants; did not evaluate swallowing; Used Disease Activity Score in 28 joints (DAS-28) to evaluate severity-number of joints not taking into account amount of pain, etc.

epidemiological investigation examined questionnaire responses in 100 participants with RA to evaluate voice and swallowing disorders associated with this autoimmune condition. There were three specific aims related to this study: (1) *to provide data regarding the prevalence of voice and swallowing disorders in the RA population,* (2) *to identify risk factors for voice and swallowing disorders in RA, and* (3) *to better understand the functional, social, occupational, and emotional effects of voice and swallowing disorders in RA.*

METHODS

Participants

Participants included 100 adults (ages 18 and older) identified and recruited from the RA population. A chart review of patients attending the Division of Rheumatology at University Hospital, The University of Utah Health Care over the past 3 years was undertaken, using diagnosis codes associated with this disease. The medical records of eligible participants were subsequently reviewed to verify diagnosis. Criteria for RA diagnosis included the presence of rheumatoid factor, anticyclic citrullinated peptide igG antibodies, and one or more of the following symptoms: morning joint stiffness, arthritis of three or more joint areas, arthritis of hand joints, symmetric arthritis, rheumatoid nodules, and/or radiographic changes (Vitali et al., 2002). Consecutive patients with RA diagnosis were identified and invited to participate until 100 participants were enrolled. Inclusion criteria were the RA diagnosis, absence of SS diagnosis, age 18 or older, English-speaking, adequate hearing for purposes of telephone interview, and no known or reported cognitive deficits. The chart review identified 235 eligible participants who were subsequently invited to participate. Of these, 110 did not return the researcher's phone calls, and 25 declined; therefore, the final group of participants included 100 participants with RA, or 42% of eligible participants.

Once identified, prospective eligible participants received a letter indicating that they would receive a call regarding possible study participation, and that they might opt

out of the call by calling the principal investigator. The envelope included two copies of the consent form and a postage-paid return envelope. Subsequently, these participants received a telephone call by the co-investigator providing details about the study and inviting the individual to participate. If the individual was interested in participating, the consent form was reviewed via telephone and then the individual was instructed to sign and return one copy of the consent form to the investigator. A time for telephone administration of the questionnaire was then scheduled, allowing time for return of the consent form. Once the signed consent form was received, the questionnaire was administered via telephone. The participant was instructed that she or he could choose to withdraw from the study and cancel the telephone questionnaire at any time. Interviews were conducted over a 9-month period from 2012 to 2013 by a graduate or undergraduate student in the Department of Communication Sciences and Disorders at The University of Utah. This study was approved by the Institutional Review Board at the University of Utah (IRB#00058438).

Data Collection

The questionnaire (see Appendix) in the present investigation included a comprehensive, 45-item questionnaire involving medical, lifestyle, psychosocial, and occupational factors, voice and swallowing symptoms, and individual disease severity scales. For the purpose of this study, we considered a voice disorder to be "any time the voice does not work, perform, or sound as it normally should, so that it interferes with communication" (Roy et al., 2005). This case definition of a voice disorder was previously used in the largest National Institutes of Health epidemiology study of voice

disorders in the U.S. (R01 DC02285 Elaine Smith, Principal Investigator, National Institute on Deafness and Other Communication Disorders). A swallowing disorder was considered to be "any time an individual experiences difficulty moving food or liquid from mouth to stomach, or experiences choking or throat clearing during or following mealtime" (Roy, Stemple, Merrill, & Thomas, 2007). This definition of a swallowing disorder is the conventional and accepted definition of dysphagia currently employed in basic and applied research and in contemporary texts dedicated to the topic of dysphagia. Thus, the questionnaire probed the domains of both voice and swallowing history to identify symptoms and signs, practices and patterns, and related these findings to medical, psychosocial, occupational, and social and lifestyle factors. The questionnaire required approximately 75 minutes to complete. The questionnaire consisted of six primary sections detailed below.

Medical History

Voice production and swallowing function are influenced by a variety of medical conditions. We selected 21 conditions/disorders with the potential to influence the structures and/or function of voice and swallowing and considered the presence or absence of these conditions in the participant's lifetime and, if appropriate, mechanisms of medical treatment. The inclusion of the 21 disorders was based upon examination of previously employed questionnaires, review of current literature (Roy et al., 2005; Roy, Merrill, Thibeault, Gray, et al., 2004; Roy, Merrill, Thibeault, Parsa, et al., 2004), and the clinical experience of investigators. This section also included more detailed questions regarding upper respiratory concerns and the use of medications.

Psychosocial History

Psychosocial factors may contribute to and be affected by voice and swallowing disorders (Roy, Stemple, Merrill, & Thomas, 2007a; Roy et al., 2007b). This section of the questionnaire probed two main areas within the psychosocial domain, including psychosocial risk factors, such as gender and activity level, as well as the psychosocial impact of voice and swallowing disorders. Three standardized batteries, the Voice-Related Quality of Life (V-RQOL; Hogikyan & Sethuraman, 1999), the M.D. Anderson Dysphagia Inventory (MDADI; Chen et al., 2001), and the Short Form 36 Health Survey (SF-36; Ware, Gandek, & International Quality of Life Assessment Project Group, 1994) were included to comprehensively examine the impact of voice and swallowing disorders in this population and the relation of these disorders to general health. The MDADI is a psychometrically-validated, dysphagia-specific instrument that assesses psychosocial aspects of dysphagia. The V-RQOL is a validated, reliable, 10-item instrument that has been used to determine the impact of voice impairment on quality of life and as an outcome measure in participants with voice disorders. The SF-36 is a psychometrically validated questionnaire. The SF-36 was developed to assess eight different measures of functional health and well-being. The SF-36 is a generic tool in that it does not target a specific age, disease, or treatment group. The relative health burden of eight profiles (physical functioning, bodily pain, role limitations due to physical health problems, role limitations due to emotional problems, emotional well-being, social functioning, energy/fatigue, and general health perceptions) can be established. In addition, two composite/summary measures of physical and mental health are generated. Four scales reflect different dimensions of physical health and four scales reflect different dimensions

of mental health. In addition to the SF-36, an additional question involving how the participant felt on a daily basis was also included.

Occupational or Employment History

Research has identified a link between occupation and the risk of voice disorders (Roy et al., 2005; Roy, Merrill, Thibeault, Gray, et al., 2004; Roy, Merrill, Thibeault, Parsa, et al., 2004); however, the relationship between occupation and swallowing problems has not been documented. This questionnaire examined aspects of the participant's occupational history in order to determine its potential role in voice symptomology. This section examined work history, job-related voice use patterns, and the participant's perception of the impact of job-related voice use on voice production.

Social and Lifestyle History

Lifestyle patterns and choices may influence voice and swallowing (Roy et al., 2005; Roy et al., 2007a, 2007b). Diet may influence these processes via its impact on hydration and on levels of harmful stomach acid refluxing into the larynx and pharynx. The use of tobacco products, alcohol, and recreational drugs may also influence function by altering the hydration and integrity of tissues in the aerodigestive tract. This section probed the participant's dietary history, such as caffeine intake, consumption of dairy products, or the intake of spicy foods, as well as their history of using tobacco products, alcohol, and recreational drugs.

Voice and Swallowing Problem History

Rates of voice and swallowing disorders seem higher among patients with RA (Beirith, Ikino, & Pereira, 2013; Roy et al., 2005; Speyer et al., 2008). However, a comprehensive description of the etiology, onset, course, presentation, and treatment of these conditions in participants with RA has yet to be developed. The questionnaire examined details of the participant's current and/or previous voice and swallowing concerns with the intention of clearly defining correlates of voice and swallowing concerns, patterns of change across the lifespan, typical disease-related features, rates of treatment seeking, and outcomes.

Disease Severity

Numerous items in the questionnaire rated the severity of specific symptoms, general health, and the autoimmune condition. Along with these items included in the main body of the questionnaire, severity appendices were administered specific to various autoimmune diagnoses. To assess severity of RA, the Rheumatoid Arthritis Pain Scale (RAPS) was included (Anderson, 2001). The RAPS was developed to measure pain in adult patients with RA. Items on this scale are scored using a seven-point Likert scale ranging from "0-never" to "6-always" with a higher score considered to represent greater severity of pain. These scores were compared with severity scales of voice and swallowing to determine relationships among comorbid conditions and symptoms.

The questionnaire construction, as described above, facilitated understanding of the prevalence of voice and swallowing disorders in RA. Further, it permitted consideration of interactions among the above domains, including the delineation of risk

factors, prognostic indicators, treatment outcomes, and functional implications. Consistency and accuracy of questionnaire administration was ensured using three primary methodologies. First, all research assistants received individual training and instruction on questionnaire administration. They were permitted to ask questions and take notes regarding administration and response to participant questions. Second, each research assistant was required to practice administering the questionnaire to nonparticipants prior to interviewing participants. Third, research assistants were audited periodically via questionnaire instrument data entry and through bimonthly research team meetings to ensure accuracy of questionnaire administration. Interrater reliability was calculated on 10% of the questionnaires.

Statistical Analyses

Conventional data analyses procedures used in other epidemiology studies conducted by this group (Roy et al., 2007a, 2007b; Tanner et al., 2011) were employed. Medical, familial, environmental, and social history data were examined using contingency tables, summary statistics, chi square tests, and risk ratios. In the following section, data analysis procedures are described in detail.

The prevalence and severity of voice and swallowing problems was evaluated using descriptive statistics. Variables were examined using contingency tables and multiple logistic regression. Bivariate analyses of association were evaluated for statistical significance using the chi square (χ^2), the Mantel-Haenszel Chi square (MH χ^2), and the Cochran-Mantel-Haenszel Statistic (CMH). The χ^2 is used to test for independence between variables, the MH χ^2 is used to test for differences in trends

between variables, and the CMH is used to test for independence after adjusting for potential confounding factors. Tests that beta coefficients in the logistic regression models equal zero were based on the Wald test, which follows an approximate χ^2 distribution.

Cross-tabulations were used to perform bivariate analyses between selected variables, with statistical significance based on the chi-square test for independence (χ^2). The *t* statistic was used for testing the null hypothesis of equality of means between groups (i.e., those with voice and swallowing disorders versus those without), with the *t* statistic computed using approximate degrees of freedom from Satterthwaite's approximation when the variances between the two groups were unequal. In addition, unadjusted and adjusted (controlling for the presence of other variables) RRs were estimated using logistic regression to establish specific risk factors for reporting voice disorders. The association between history of a voice disorder and presence of selected risk factors (e.g., employment classification, work-related voice use issues, history of gastroesophageal reflux disease, frequent colds /sinus infections, chemical exposure, and many other disease entities) was assessed for homogeneity across the levels of age and sex using the Breslow-Day test for homogeneity. Multiple logistic regression modeling was employed, with interaction terms among significant main effects evaluated in the model.

Risk ratios (RRs) can range from 0 to infinity. The RR is statistically significantly different than 1.0 at the 0.05 level of significance if the 95% confidence interval (CI) does not include 1.0. A RR of less than 1 indicates a negative association, a RR of 1 indicates no association, and a RR of more than 1 indicates a positive association

between two variables. If both the lower and upper limits of the Cl are less than 1, there is a significant negative association, whereas if both the lower and upper limits of the Cl are greater than 1, there is a significant positive association. RRs may be interpreted literally, and describe the extent to which the likelihood of possessing a particular risk factor (i.e., a specific health condition) increases the presence of a voice disorder. For example, participants with RA who have a voice disorder might be 1.5 times as likely to possess the specified health condition versus participants with RA who did not report voice problems.

Finally, whether the relationship between severity of voice or swallowing disorders and selected dichotomous risk factors depends on duration, frequency, sex, and age, was addressed by assessing interaction terms among the significant main effects in multiple regression models. Only variables significant at the 0.2 level, based on backward stepwise logistic regression, were retained in the model. This conservative value was used to minimize the probability of committing a type I error. Two-sided tests of significance were based on the 0.05 level against a null hypothesis of no association. Analyses were performed using SAS version 9.1 (SAS Institute Inc., Cary, NC, USA, 2003). Procedure statements used in SAS for assessing the data included PROC FREQ, PROC GLM, PROC FACTOR, PROC TTEST, and PROC LOGISTIC.

Results

Demographics

The participants ranged in age from 29.3 to 95.1, with mean age 61.1 ($SD = 13.1$). A description of the 100 participants is shown in Table 2. Most were women, non-Hispanic Whites, had a current household yearly gross income of $60,000 or more, and had at least some college education.

Years with RA ranged from 1 to 50, with a mean of 19.6 ($SD = 13.4$). The number of participants currently taking medication for RA was 95 (95%), ranging in years from 1 to 47 ($M = 15.6$, $SD = 12.4$). Years with RA and whether medication was currently being used for RA was not significantly associated with age, sex, race/ethnicity, income, or education. Among the 100 RA participants, only 8 had another autoimmune condition in addition to RA; 4 had Sjögren's Syndrome (SS), 1 of whom also had Mixed Connective Tissue Disease (MCT), and 4 had Type 1 Diabetes. The remaining 92 participants had RA exclusively. A description of comorbid autoimmune conditions is shown in Table 3.

A RA severity index score was obtained via the Rheumatoid Arthritis Pain Scale (RAPS) (Anderson, 2001). Scores ranged from the least severe with a score of 0 to most severe with a score of 150 ($M = 65.1$, $SD = 41.6$). The severity score was not significantly associated with years with RA, whether medication was currently being used to treat RA,

Table 2. Description of participants

	n	%
Age		
20-39	7	7.0
40-59	12	12.0
60-69	26	26.0
70-79	27	27.0
80+	28	28.0
Sex		
Men	16	16.0
Women	84	84.0
Ethnicity/Race		
NH–White	91	91.0
NH–Asian	2	2.0
NH–Native American/Alaska Native	2	2.0
Hispanic	5	5.0
Household Yearly Gross Income		
< $20,000	14	14.7
$20,000-$39,999	22	23.3
$40,000-$59,999	10	10.5
$60,000+	49	51.6
Missing	5	
Education		
< High School	7	7.0
High School	17	17.0
Some College	35	35.0
College Bachelors Degree	19	19.0
Graduate Training/Degree	22	22.0

Table 3. Distribution of autoimmune conditions in the cohort

	n	%
RA only	92	92.0
RA + SS	3	3.0
RA + Diabetes Type 1	4	4.0
RA + SS + MCT	1	1.0

or years of medication use. The RA severity score did not significantly differ across levels of sex, race, ethnicity, or income, but significantly decreased with age ($M = 94.6$ for ages 20-39, $M = 90.6$ for ages 40-59, $M = 73.0$ for ages 60-69, $M = 67.0$ for ages 70-79, and $M = 53.7$ for ages 80+, $p < 0.0344$). RA severity also decreased with education ($M = 100$ for < HS, $M = 87.8$ for HS, $M = 72.2$ for some college, $M = 67.1$ for college degree, and $M = 50.9$ for some graduate/graduate degree).

Prevalence of Voice Disorders

Thirty-five participants with RA (i.e., 35%) reported having a current voice disorder, and twenty (20%) reported having a voice disorder in the past. Of the participants who currently had a voice disorder, 6 (17.1%) said it began suddenly, and 29 (82.9%) reported that it began gradually; 30 (85.7%) reported it as a chronic problem (i.e., duration of 4 weeks or longer). For those with a voice disorder, 20% first noticed the disorder within the past year, 30% 1 to 3 years earlier, 26.7% 4 to 9 years earlier, and 23.3% 10 or more years earlier. The prevalence of a current voice disorder did not significantly differ across the levels of age, sex, race/ethnicity, income, or education. RA disease severity was not significantly related to the observed prevalence of a current voice disorder.

Voice Symptoms

The presence and frequency of selected voice-related symptoms were identified in the participant population as shown in Table 4. Participants were asked to quantify the frequency of selected voice symptoms with "daily" = 1, "weekly" = 2, "monthly" = 3,

Table 4: Levels of selected voice-related symptoms

	Current	Frequency*	Voice disorder in those with a current symptom		χ^2
Symptom	**%**	***M* (*SD*)**	***n***	**%**	***p* value**
Hoarseness	**31**	**3.8 (1.5)**	**20**	**65**	**< 0.0001**
Voice tires or changes quality after using it for a short time	**19**	**2.7 (1.4)**	**16**	**84**	**< 0.0001**
Trouble speaking or singing softly	**24**	**2.8 (1.4)**	**13**	**54**	**0.0211**
Difficulty projecting your voice	**20**	**3.2 (1.5)**	**13**	**65**	**0.0019**
Loss of singing range	33	2.4 (1.4)	16	48	0.0533
Discomfort while using your voice	**17**	**2.9 (1.4)**	**12**	**71**	**0.0007**
A monotone voice (monopitch)	6	3.0 (1.4)	3	50	0.4163
Takes effort to talk	**11**	**3.6 (1.3)**	**9**	**82**	**0.0004**
Chronic dryness in your throat	**36**	**1.7 (1.1)**	**21**	**58**	**0.0002**
Wet, gurgley voice quality	**9**	**3.5 (1.7)**	**7**	**78**	**0.0044**
Chronic soreness in your throat	7	3.1 (1.6)	4	57	0.1954
Frequently clear your throat	**48**	**2.2 (1.6)**	**27**	**56**	**< 0.0001**
A bitter or acid taste	23	2.8 (1.5)	11	48	0.1304
Wobbly or shaky voice	10	3.2 (1.6)	6	60	0.0760
An "airy" or "breathy" voice	**9**	**3.6 (1.4)**	**6**	**67**	**0.0345**

*1 = Daily, 2 = Weekly, 3 = Monthly, 4 = Several times a year, 5 = Yearly or less

"several times a year" = 4, and "yearly or less" = 5. The mean frequency of the selected voice symptoms ranged from 1.7 to 3.8 monthly ($M = 3.0$, $SD = .6$). Ten of the 15 voice-related symptoms were significantly associated with the participants currently having a voice disorder.

Voice Use Patterns, General Health, Lifestyle, and Voice Disorders

To assess the impact of participants' voice use patterns, general health, and lifestyle on experiencing a current voice disorder, they were asked questions related to each of these areas. RRs for the significant variables were also determined in order to report how much more likely someone who possesses the respective attribute or condition is to report a voice disorder, versus someone who does not have the attribute or condition. Questions regarding voice use patterns were asked to establish the frequency of specific vocal behaviors during the day, vocally-demanding jobs, and any job-related voice

disorders. Participants were asked general health questions to establish the history of specific medical conditions and coinciding medication use, history of environmental inhalants, bodily tension, and family history of voice and swallowing problems. Lifestyle questions were asked regarding use of tobacco, alcohol, and drugs, as well as exercise patterns and personality descriptors. Table 5 lists each condition addressed, the number of participants with each condition who also reported a current voice disorder, the resulting significance patterns, and RRs. The self-reported factors associated with significantly elevated RRs, from greatest to least, include neck/throat tension (RR = 2.4), job-related voice disorder (RR = 2.4), jaw tension (RR = 2.3), vocally-demanding occupation (RR = 2.3), sleep disorder (RR = 1.8), and being physically active (RR = .5).

The association between several selected variables and a voice disorder was assessed in Table 5. Of the comorbid medical conditions assessed, only sleep disorder was significantly associated with a current voice disorder; that is, of those with a sleep disorder, 48.6% had a voice disorder compared with 27.7% of those without a sleep disorder. Additionally, a voice disorder was significantly more common among those who often/constantly experienced tension in their neck/throat or jaw, among those who were quiet versus talkative, and among those who were physically inactive versus active. Colds, sinus infections, and sore throats were not significantly associated with a voice disorder. Having had head and neck surgery, chest/thoracic surgery, abdominal surgery, or any other surgery was not significantly associated with having a voice disorder. Previously having a tracheostomy tube or having been on a respirator/ventilator/breathing machine was not significantly associated with having a voice disorder. Having used tobacco products for a year of longer or ever using recreational drugs were not

Table 5: Current voice disorder and selected conditions

Medical Condition	***n***	**RR**	**95% CI**	χ^2 ***p***
Experience tension (often/constantly vs. otherwise)				
Neck/Throat	**38**	**2.4**	**1.4-4.2**	**0.0009**
Jaw	**15**	**2.3**	**1.4-3.7**	**0.0055**
Shoulders	42	1.3	0.8-2.2	0.3310
Abdomen	5	1.8	0.8-3.8	0.2315
Sleep disorder	**35**	**1.8**	**1.0-3.0**	**0.0368**
Family history of any type of voice problem	5	1.2	0.4-3.5	0.8099
Ever in an occupation requiring you to talk a lot on a daily basis	**77**	**2.3**	**0.9-5.9**	**0.0436**
Experience voice disorders with this job	**26**	**2.4**	**1.4-4.0**	**0.0014**
Exposures				
Excess dust – current	15	1.2	0.6-2.3	0.6597
Excess dust – past	41	1.0	0.6-1.7	0.8814
Fumes from cleaning products– current	26	1.5	0.9-2.5	0.1657
Fumes from cleaning products – past	46	1.2	0.7-2.1	0.4265
Secondary tobacco smoke– current	11	0.8	0.3-2.1	0.5690
Secondary tobacco smoke – past	64	1.1	0.6-1.9	0.7933
Dry air– current	83	1.6	0.6-3.9	0.2764
Dry air – past	90	3.8	0.6-24.7	0.0821
Exercise (yes vs. no)	80	0.8	0.5-1.6	0.6002
Personal description				
Quiet vs. talkative	44	1.7	1.0-2.9	0.0520
Easy-going vs. worrier	69	0.8	0.4-1.3	0.3297
Active vs. inactive	**76**	**0.5**	**0.3-0.9**	**0.0239**
Happy vs. sad	93	1.2	0.4-4.1	0.7116

significantly associated with a voice disorder.

In addition, on a scale from 1 (never) to 5 (constantly), mean scores of clearing one's throat were 3.5 ($SD = 1.0$) for those with a voice disorder compared with 3.0 ($SD = 1.1$) for those without a voice disorder ($t = 2.15$, $p = .0340$). Mean scores for cough were 2.9 ($SD = 1.0$) for those with a voice disorder compared with 2.5 ($SD = 0.8$) for those without a voice disorder ($t = 2.2$, $p = .0310$).

In addition, regression analysis showed that after adjusting for both age and education, the RA severity score was simultaneously significantly associated with current

chronic dryness in the throat (Partial $r^2 = 7.4$, $p = 0.0044$), trouble with speaking or singing softly (Partial $r^2 = 4.8\%$, $p = .0177$), and voice tiring or changing quality after using it for even a short time (Partial $r^2 = 3\%$, $p = 0.0558$). Having a voice disorder was significantly greater among those who reported that they were in poorer health (Table 4). V-RQOL was not significantly associated with health but RA severity index did significantly increase with poorer health. While the severity of RA was not significantly associated with having a voice disorder, RA severity was significantly positively associated with trouble speaking or singing softly, frequently clearing their throat, and bitter or acid taste. Hoarseness, chronic dryness in their throat, and wet, gurgley voice quality were marginally insignificant.

Voice Disorders and Quality of Life

To assess the functional impact of a voice disorder on the RA population, several quality-of-life measures were included in the survey. These measures were associated with current voice disorders, current voice symptoms, and RA severity. The V-RQOL, a measure of the impact of having a voice disorder on quality of life, ranged from 35 (poorest QOL) to 100 (best QOL) with a mean of 90.1 ($SD = 14.3$). V-RQOL was not significantly associated with age, sex race, ethnicity, income, or education, but was significantly related to whether the patient indicated having a voice disorder with a mean of 80.9 ($SD = 17.3$) for those with a voice disorder versus a mean of 95.0 ($SD = 9.3$), ($p < 0.0001$). Mean V-RQOL was significantly lower for all of the selected voice-related symptoms except chronic soreness in your throat and a bitter or acid taste, as shown in Table 6. Regression analysis showed that the V-RQOL measure was simultaneously

Table 6: Voice symptoms and relation with V-RQOL Scores

	Voice-Related Quality of Life		
Symptom	No Current Symptom	Current Symptom	
	M (*SD*)	M (*SD*)	*t* statistic *p* value
Hoarseness	**92.5 (11.7)**	**84.7 (18.0)**	**0.0115**
Voice tires or changes quality after using it for a short time	**92.9 (11.6)**	**77.2 (18.1)**	**< 0.0001**
Trouble speaking or singing softly	**78.7 (20.0)**	**93.5 (9.8)**	**< 0.0001**
Difficulty projecting your voice	**73.6 (17.5)**	**94.1 (9.9)**	**< 0.0001**
Loss of singing range	**83.3 (17.5)**	**93.3 (11.2)**	**0.0008**
Discomfort while using your voice	**79.5 (15.6)**	**92.2 (13.1)**	**0.0006**
A monotone voice (monopitch)	**91.2 (12.8)**	**69.3 (22.8)**	**0.0002**
Takes effort to talk	**92.1 (12.5)**	**73.5 (18.2)**	**< 0.0001**
Chronic dryness in your throat	**94.0 (10.4)**	**82.8 (14.5)**	**0.0001**
Wet, gurgley voice quality	**92.1 (11.3)**	**67.7 (22.5)**	**< 0.0001**
Chronic soreness in your throat	90.3 (14.6)	85.1 (11.9)	0.3693
Frequently clear your throat	**95.7 (8.0)**	**83.9 (17.0)**	**< 0.0001**
A bitter or acid taste	91.3 (14.6)	85.2 (13.3)	0.0759
Wobbly or shaky voice	**92.2 (11.3)**	**69.5 (22.2)**	**< 0.0001**
An "airy" or "breathy" voice	**91.2 (13.1)**	**77.0 (20.5)**	**0.0044**

significantly associated with difficulty projecting your voice (Partial $r^2 = 33.2\%$, $p < 0.0001$), trouble speaking or singing softly (Partial $r^2 = 8\%$, $p = 0.0005$), wobbly or shaky voice (Partial $r^2 = 7\%$, $p = 0.0006$), frequently clear your throat (Partial $r^2 = 4.2\%$, $p = 0.0051$), a monotone voice (Partial $r^2 = 3.2\%$, $p = 0.0115$), and your voice tires or changes quality after using it for even a short time (1%, $p = 0.0458$). Together, these six voice symptoms explained 57.6% of the variation in V-RQOL.

To assess the relationship between daily, overall health and the potential effects on the voice, RA severity, and quality of life, an additional single-question measure was used. Along with specific voice symptoms, "how you feel, overall, on a daily basis" was compared with reporting a voice disorder, V-RQOL, and RAPS score. As reported in Table 7, reductions in reported overall health were significantly associated with the presence of a voice disorder and worsening disease severity. There was not, however, a

Table 7: "How you feel on a daily basis" and relation with presence of a current voice disorder with V-RQOL and RAPS scores

		Voice Disorder		V-RQOL	RA Severity Index
How feel on a daily basis	No	Yes %	No %	Mean	Mean
Excellent	18	5.6	94.4	91.1 (7.3)	41.7 (35.2)
Good	49	42.9	57.1	90.5 (15.0)	53.6 (38.3)
Fair	29	41.4	58.6	85.4 (15.8)	92.7 (31.3)
Poor	4	25.0	75.0	91.5 (11.4)	110.0 (40.1)
			χ^2 p = 0.0309	F p = 0.0967	**F p < 0.0001**

significant association between reductions in overall health and reductions in voice-related quality of life.

The general quality-of-life measure, the SF-36, and its subscales were compared with V-RQOL, the presence of a current voice disorder, and current voice symptoms. The two summary measures of the SF-36 are physical health and mental health. Each summary measure is associated with four subscales (Physical Health: physical function, role-physical, bodily pain, general health; and, Mental Health: vitality, social functioning, role-emotional, mental health). The raw scores from the questionnaire are coded into a 0 to 100 scale, with 100 representing the highest state of health. Average scores for each of the scale items across all participants have been reported previously, ranging from the 70s for general health, bodily pain, and energy/fatigue, to the 80s for social functioning, physical functioning, role limitations – physical health, and emotional well-being, to the 90s for role limitations – emotional stresses. The highest possible score for physical functioning is obtained by performing all types of physical activity including the most vigorous without limitations due to health; for role-physical is obtained by having no problems with work or other daily activities; for bodily pain is obtained by having no

pain or limitations due to pain; for general health is obtained by evaluating personal health as excellent; for energy/fatigue is obtained by feeling full of pep and energy all the time; for social functioning is obtained by performing normal social activities without interference due to physical or emotional problems; for role – emotional is obtained by having no problems with work or other daily activities; and for mental health is obtained by feeling peaceful, happy, and calm all of the time. Both SF-36 summary measures and six of its eight subscales were significantly correlated with the V-RQOL, as shown in Table 8. Table 9 identifies the extent that selected voice symptoms influenced specific quality of life domains as assessed by the SF-36. Specific voice symptoms were statistically correlated with subscales, namely: hoarseness, trouble speaking, loss of singing range, discomfort, chronic dryness, chronic soreness, frequent throat clearing, bitter or acid taste, and wobbly or shaky voice.

Thirteen participants (37% of those with a voice disorder) had ever sought professional help to improve their voice, including 8 from a speech-language pathologist, 1 from a physician, 1 from both a speech-language pathologist and a physician, and 3 from a singing or acting teacher or coach. Nine of these participants (76%) indicated that the professional help they received was beneficial. The decisions to seek professional help to improve their voices were not significantly associated with age, sex, race, ethnicity, income, or education. Voice-related help-seeking was significantly associated with sleep disorder; that is, those who ever had a sleep disorder were significantly more likely to seek voice-related professional help, with 25.7% compared to 6.2% ($\chi^2 p = 0.0055$). Those currently taking medication for esophageal reflux were less likely

Table 8. Mean SF-36 subscales and correlations with VRQOL scores

	M	*SD*	Correlation Coefficient (r) with VRQOL	Correlation Coefficient *p* value
PHYSICAL Health	**50.1**	**23.7**	**.39**	**< .0001**
Physical Functioning	**59.2**	**28.5**	**.33**	**.0009**
Role-Physical	**48.3**	**42.4**	**.38**	**.0002**
Bodily Pain	55.6	26.2	.20	.050
General Health	**41.1**	**20.7**	**.35**	**.0004**
MENTAL Health	**70.4**	**19.4**	**.43**	**< .0001**
Vitality	**48.2**	**24.2**	**.45**	**< .0001**
Social Functioning	**77.8**	**24.3**	**.45**	**< .0001**
Role-Emotional	**83.0**	**32.0**	**.38**	**.0001**
Mental Health	77.7	18.1	.17	.086

Table 9. Mean SF-36 subscale scores according to current voice symptoms

		PF		RP		BP		GH		VT		SF		RE		MH	
	n	Slope	*SE*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Hoarseness	**31**											**-10.2**	**5.0**				
Voice tires	19																
Trouble speaking	**24**							**-10.2**	**4.6**								
Difficulty projecting	20																
Loss of singing range	**33**									**-9.4**	**4.7**						
Discomfort	**17**			**-29.9**	**11.1**					**-19.1**	**6.0**	**-16.4**	**6.4**	**-22.0**	**7.9**	**-18.6**	**4.6**
Monotone	6																
Effort	11																
Chronic dryness	**36**	**-17.4**	**5.7**					**-8.8**	**4.2**	**-11.9**	**4.7**	**-10.2**	**4.9**	**-16.7**	**6.2**	**-8.1**	**3.5**
Gurgley voice	9																
Chronic soreness	**7**							**-26.2**	**7.4**								
Frequent throat clear	**48**			**-19.1**	**8.2**												
Bitter or acid taste	**23**					**-14.0**	**6.1**										
Wobbly/shaky	**10**													**-27.1**	**9.5**		
Airy/breathy	9																

Note. Only significant slope estimates appear in the table, $p < .05$.
Physical Health: Physical Function (PF), Role-Physical (RP), Bodily Pain (BP), General Health (GH)
Mental Health: Vitality (VT), Social Functioning (SF), Role-Emotional (RE), Mental Health (MH)

to seek professional help, with 7.7% compared to 26.3% ($p = 0.0536$), based on 58 who had ever had esophageal reflux; those currently taking medication for pneumonia were significantly more likely to seek professional help, with 66.7% compared to 11.1% ($p = 0.0104$), based on 39 who had ever had pneumonia; and those currently taking medication for bronchitis were significantly more likely to seek professional help, with 100% compared to 17.1% ($p = 0.0049$), based on 43 who had ever had bronchitis. There was no significant association between seeking professional help and comorbid autoimmune conditions, breathing assistance, tobacco use, tension, or family history of voice problems.

Discussion

The results of this investigation suggest that voice disorders are relatively common within the RA population. Of the 100 participants surveyed, 35% reported a current voice disorder. This represents a much higher frequency of voice disorders as compared to the 6.6% in the general population (Roy, Merrill, Gray, & Smith, 2005). Of the 35 participants who reported a current voice disorder, 82.9% described it as beginning gradually with symptoms persisting for more than 4 weeks (85.7%). Many participants (50.0 %) described the problem as longstanding (i.e., > than 4 years). Participants with RA reported numerous voice symptoms, most of which were significantly associated with reporting a current voice disorder. Frequent throat clearing occurred in nearly half of participants (48%), with many participants also reporting chronic throat dryness (36%), hoarseness (31%), and loss of singing range (33%). Thus, it appears that RA is a disease

entity associated with high rates of current voice disorders and symptoms. In the following section, we discuss the relation of voice disorders to a variety of risk factors.

This study examined associated medical conditions and risk factors that potentially contributed to voice disorder reporting. Certain medical conditions and lifestyle or occupational factors increased vulnerability for experiencing a voice disorder. Inspection of the results revealed that a voice disorder was more common among those who often/constantly experienced tension in their neck/throat or jaw, which could be associated with excess effort to produce voice. A voice disorder was more common among those who were quiet versus talkative, and among those who were physically inactive versus active. Being quiet could contribute to, or be a result of, a current voice disorder. Similarly, inactivity could be a consequence of poor health, or could contribute to further manifestations of poor health, such as voice symptoms. Interestingly, of the comorbid medical conditions assessed, only sleep disorder was significantly associated with a current voice disorder. Sleep disorder could contribute to voice problems, or discomfort and pain could cause difficulty sleeping.

Another interesting observation was that the severity of RA was not significantly associated with having a voice disorder. The RAPS is primarily an evaluation of pain, which may more accurately assess management of pain associated with RA than other symptoms that may accompany the disease. The findings of this study are consistent with past studies. Beirith, Ikino, and Pereira (2013) used the disease activity score in 28 joints (DAS-28) to evaluate disease activity and found no association between disease activity and presence of a voice disorder. Another study done by Liu, Masterson, Sroui, Musonda, and Scott (2012) found that voice symptoms were more prevalent in

participants with autoimmune disease regardless of whether they were on a disease-modifying drug.

Clearing one's throat and coughing were more common in those with a voice disorder, which may be symptoms of, or may contribute to, a voice disorder. Coughing and throat clearing are known to be vocally violent behaviors that can cause irritation to vocal fold tissue, but are also a common response to laryngeal irritation (Bonilha, Gerlach, Sutton, Dawson, & Nietert, 2012). There seemed to be no association, however, between other potentially phonotraumatic behaviors, such as prolonged speaking or shouting. There was also no association seen between a voice disorder and frequent use of refluxogenic agents such as spicy foods or caffeine, which could cause reflux and contribute to irritation of the larynx.

Effects of Voice Symptoms and Disorders on Quality of Life in RA

As expected, voice-related quality of life was significantly associated with whether the patient indicated having a voice disorder. Interestingly, mean V-RQOL was significantly lower (worse) for all of the examined voice-related symptoms except chronic soreness in the throat and a bitter or acid taste. Participants with RA reported a lower V-RQOL when they experienced difficulty projecting the voice, trouble speaking or singing softly, wobbly or shaky voice, frequently clear your throat, a monotone voice, and the voice tires or changes quality after using it for even a short time. Perceptual changes in quality such as breathiness or hoarseness were not significantly associated with changes in V-RQOL.

Voice disorders contribute to significantly reduced overall quality of life as assessed by the SF-36. There was a significant difference in mean summary of mental health in those with a current voice disorder compared to those without. Current voice disorders appeared to have more of an impact of mental rather than physical quality of life. Previous studies examining the impact of voice disorders on quality-of-life have found an impact on both physical and emotional health (Roy et al., 2005; Roy et al., 2007, Merrill et al., 2013). A study completed by Merrill, Roy, and Lowe (2013) showed all voice symptoms having significant negative correlations with general health, bodily pain, and vitality, of which, only vitality was a common finding with the present study. Table 9 identifies the extent that selected voice symptoms influenced specific quality-of-life domains as assessed by the SF-36. Specific voice symptoms were statistically correlated with subscales, namely: hoarseness, trouble speaking or singing softly, loss of singing range, discomfort while using voice, chronic dryness, chronic soreness, frequent throat clearing, bitter or acid taste, and wobbly or shaky voice. These symptoms seemed to particularly contribute to reductions in health summary measures of quality of life.

An additional quality-of-life survey question, "how do you feel, overall, on a daily basis," was significantly correlated with reporting a voice disorder, and RA severity. Similar to the VRQOL and the SF-36, this question was significantly associated with specific voice symptoms, including frequent throat clearing and cough. Frequent throat clearing was significantly associated with all three QOL measures.

Fewer than half the participants with a voice disorder (37%) had sought professional help to improve their voices. 76% of patients that had sought help indicated that their voices improved. Limited patient education may be an explanation for this low

rate of seeking treatment for voice disorders. The results from this study may have important implications for referral practices and identification of symptoms within the RA population. It may be important for future research to investigate novel treatment options for voice disorders within this population.

Comparisons with the Extant Literature

In reviewing the extant literature in the area of RA and voice disorders, the studies critiqued in Table 1, along with additional studies, could not be directly compared to the current study due to methodology differences and low numbers of RA participants in many of the previous studies. General comparisons, however, were made.

The current, large-scale study sought to identify the prevalence of voice disorders within the RA population. Past studies have reported a large range of laryngeal involvement and dysphonia associated with RA. Geterud et al. (1991) found laryngeal involvement in 69% of participants. This study used a questionnaire, physical examination, and other physical measures including a blood test to determine laryngeal involvement. As this study's definition of "laryngeal involvement" was not limited to dysphonia, it is difficult to compare to results from the current study; however, the 69% reported among 29 RA participants is higher than either voice or swallowing disorders reported in the current study of 100 participants.

Beirith, Ikino, and Pereira (2013) found a 12.8% prevalence of dysphonia in 47 participants with RA, which is significantly lower than the 35% reporting a voice disorder in the current study. This study used both objective and subjective measures, incorporating disease activity score, laryngeal symptoms, the Voice Handicap Index, and

videolaryngoscopy. The disease activity score evaluates the number of joints involved, but does not evaluate levels of pain or discomfort associated with presence of RA, as does the RAPS.

Speyer et al. (2008) found dysphonia in 19% of 166 RA participants. While this study recruited a greater number of RA participants, only a visual analog scale of severity, the VHI, and a three-item outcome scale on perception of improvement were used. These measures are far less extensive than the questionnaire used in the current study, and may not have identified as many participants as having voice symptoms as a result of that. Similarly, Liu et al. (2012) reported 16.6% of participants with an autoimmune disease (only 60% of which had RA) reported significant voice symptoms.

Lofgren and Montgomery (1962) reported 26% of RA participants to have involvement of the cricoarytenoid joint, which can affect voice, swallowing, and breathing. This study recruited 100 participants with RA and identified involvement of the cricoarytenoid joint based on external palpation and indirect laryngoscopy. Because no subjective measures were used to evaluate participants' perception of effects on voice, this report of 26% may be inaccurate, particularly due to periods of remission experienced in RA. Berjawi et al. (2010) recruited only 11 participants with RA and 8 controls, but reported that 66% of RA participants had loss of range and hoarseness. The current study did result in a similar finding regarding hoarseness and loss of singing range being common symptoms in participants with RA.

In spite of differences in reported prevalence among the current study and past studies done examining effects of RA on voice disorders and symptoms, it is clear that

there is an increased prevalence of voice disorders and symptoms within the RA population and that these do have a significant adverse impact on quality of life.

Results

Prevalence of Swallowing Disorders

Of the 100 participants surveyed, 41 reported a current swallowing disorder where they experienced difficulty moving food or liquid from their mouth to their stomach or anytime they experienced chocking or frequent throat clearing during or following mealtime. A past swallowing disorder reportedly occurred in 23 participants (23.0%). Of the 41 with a current swallowing problem, 37 (90.2%) said that it lasted for more than 4 weeks and 7 (17.1%) said that the problem began suddenly. For those with a swallowing disorder, 53% had first noticed the disorder at least 4 weeks earlier, indicating that these disorders are often longstanding. . The prevalence of a current swallowing disorder did not significantly differ across the levels of age, sex, race/ethnicity, income, or education. There was no significant relationship between the frequency of comorbid autoimmune conditions and a current swallowing disorder; however, the association between a current swallowing disorder and severity of RA approached significance ($p = .08$).

Swallowing Symptoms

Levels of selected swallow-related symptoms were identified in the patient population in Table 10. Twelve of the 19 swallow-related symptoms were significantly

Table 10: Levels of selected swallowing-related symptoms and presence of a current swallowing disorder

	Participants Currently Reporting Symptom	Swallowing disorder in those with a current symptom		χ^2
Symptom	**%**	***n***	**%**	***p* value**
To take longer time to eat because of your swallowing problem	**21**	**18**	**86**	**< .0001**
Difficulty swallowing liquids	**17**	**14**	**18**	**.0002**
Difficulty swallowing solids	**32**	**26**	**81**	**< .0001**
Difficulty swallowing medications	27	14	52	.2175
A gurgley or wet voice during or after eating	10	7	70	.0580
Coughing, throat clearing, or choking before, during or after eating	**30**	**19**	**63**	**.0037**
An inability to control food, liquid, or saliva in the mouth	**8**	**4**	**50**	**.0037**
Any sneezing during or after a meal	16	7	44	.8660
Pain or pressure in the throat or chest during swallowing	**22**	**19**	**86**	**< .0001**
Wheezing after eating	5	2	40	.9322
Food comes out of your nose while eating	1	0	0	.3964
A need to chew excessively in order to swallow safely	**27**	**21**	**78**	**< .0001**
Dry mouth	**52**	**31**	**60**	**.0002**
Difficulty placing food in mouth	2	1	50	.8140
A sensation of food sticking in your throat	**28**	**20**	**71**	**.0002**
To forcibly regurgitate food that is stuck in your throat	10	6	60	.2215
To avoid eating certain foods because of your swallowing disorder	**16**	**11**	**69**	**.0176**
Increased mucous or phlegm in your throat before, during, or after you eat	**17**	**11**	**65**	**.0331**
To take smaller bites of food in order to swallow safely	**28**	**23**	**82**	**< .0001**

associated with the participants currently having a swallowing disorder. Of the 19 swallowing symptoms, the most commonly reported by far was dry mouth (52%). Other common symptoms included difficulty swallowing solids (32%), coughing, throat clearing, or choking before, during, or after eating (30%), food sticking in the throat (28%), and taking smaller bites of food in order to swallow safely (28%).

Voice Use Patterns, General Health, Lifestyle, and Swallowing Disorders/Symptoms

To assess the impact of participants' voice use patterns, general health, and lifestyle on experiencing a current swallowing disorder, the same questions compared with voice disorders above were used in analyses. RRs for the significant variables were also determined in order to report how much more likely someone who possesses the respective attribute/condition is to report a swallowing disorder, versus someone who does not have the attribute/condition. Questions regarding voice use patterns were considered for analyses to determine whether these voice patterns impacted swallowing. Table 11 lists each condition addressed, the number of participants with each condition who also reported a current swallowing disorder, the resulting correlations, RRs, and CIs. The self-reported factors associated with significantly elevated RRs, from greatest to least, include thyroid problems (RR = 2.87), current exposure to excess dust (RR = 2.63), three or more sore throats per year (RR = 2.28), past exposure to excess dust (RR = 2.03), esophageal reflux (RR = 1.97), laughing often/constantly (1.82), job-related voice disorder (RR = 1.74), current voice disorder (RR = 1.60), often/constant shoulder tension (RR = 1.59), and being physically active (RR = .61).

Table 11. Current swallowing disorder and selected conditions

	Current Swallowing Disorder		χ^2	RR	95% CI
Medical Condition	***n***	**%**	***p* Value**		
Arthritis	30	38.46	.3311		
Heart disease	4	50	.5895		
Hypertension	22	47.83	.2002		
Circulatory problems	10	41.67	.9393		
Kidney problems	10	52.63	.252		
Thyroid problems	**24**	**72.73**	**< .0001**	**2.87**	**1.81- 4.54**
Stomach or duodenal ulcer	11	52.38	.2504		
Esophageal reflux	**30**	**51.72**	**.0104**	**1.97**	**1.12- 3.48**
Stroke	2	28.57	.4881		
Respiratory allergies	11	29.73	.0791	0.62	.38- 1.09
Pneumonia	19	48.72	.2096		
Emphysema	4	80	.0689	2.05	1.24- 3.41
COPD	3	60	.3755		
Hearing loss	14	46.67	.4507		
Bronchitis	22	51.16	.0727	1.5349	.9602- 2.4536
Asthma	8	47.06	.5772		
Severe neck, back, or head injury	14	48.28	.3444		
Chronic pain	31	42.47	.6241		
Cancer	4	28.57	.3079		
Depression or anxiety	23	51.11	.063	1.5617	.9716- 2.5102
Sleep disorder	16	45.71	.4818		
Stopped menstrual periods	31	44.93	.4109		
Voice					
Current voice problem	**19**	**54.29**	**.0475**	**1.6039**	**1.0166- 2.5306**
Did the problem begin suddenly?	4	66.67	.5036		
Did the problem last more than 4 weeks?	16	53.33	.7817		
Past voice problem	12	60	.0534	1.6552	1.0439- 2.6245
Family history of any type of voice problem	1	20	.3273		
Medications for the following conditions					
Bronchitis	1	50	.9731		
Asthma	4	50	.8188		
Severe neck, back, or head injury	2	40	.6839		
Chronic pain	23	40.35	.4902		
Sore throat (3+ vs. < 3 year)	**32**	**35.96**	**.0035**	**2.2756**	**1.5360- 3.3712**
Cancer	0				
Depression or anxiety	15	60	.1823		
Sleep disorder	12	60	.0501	2.2500	.9036- 5.6027
Condition					
Colds (3+ vs. < 3 year)	33	40.74	.9134		
Sinus infections (3+ vs. < 3 year)	33	37.5	.054	1.7778	1.0973- 2.8802
Post nasal drip (Chronically vs. less)	20	37.04	.3827		
Head and neck surgery	14	40	.8019		
Breathing assistance	8	47.06	.5772		
Ever used tobacco products	11	35.48	.4522		
At any year in your life, drank an average of one or more alcoholic beverages a week.	21	48.84	.1664		
Ever used recreational drugs	7	38.89	.8406		
Experience tension					

Table 11. Continued

	Current Swallowing Disorder		χ^2	RR	95% CI
Neck/Throat (often/constantly vs. otherwise)	22	35.48	.152		
Jaw	32	37.65	.1046		
Shoulders	**15**	**25.86**	**.0003**	**1.5938**	**.9710- 2.6160**
Abdomen	37	38.95	.0689	2.3937	1.4574- 3.9312
Family history of any type of swallowing problem	6	42.86	.8789		
Voice activity					
Talk (often/constantly vs. otherwise)	5	35.71	.6646		
Talk quietly	24	42.86	.6701		
Whisper	41	41.84	.2337		
Talk loudly	28	36.36	.0846	1.5543	.9768- 2.4734
Sing	34	40	.6284		
Shout, yell or cheer	41	42.71	.0888		
Clear your throat	21	35	.1352		
Laugh	**10**	**27.03**	**.0295**	**1.8206**	**1.0134- 3.2709**
Cough	31	37.35	.101		
Ever in an occupation requiring you to talk a lot on a daily basis	34	44.16	.2404		
Experience voice disorders with this job	**16**	**61.54**	**.0283**	**1.7436**	**1.0789- 2.8179**
Exposures					
Excess dust – current	**13**	**86.67**	**< .0001**	**2.6310**	**1.8310- 3.7804**
Excess dust – past	**24**	**58.54**	**.003**	**2.0316**	**1.2613- 3.2723**
Fumes from cleaning products– current	13	50	.2781		
Fumes from cleaning products – past	21	45.65	.3827		
Secondary tobacco smoke– current	5	45.45	.7502		
Secondary tobacco smoke – past	26	40.63	.919		
Dry air– current	33	39.76	.5772		
Dry air – past	38	42.22	.456		
Exercise (yes vs. no)	30	37.5	.1547		
Description					
Quiet vs. talkative	19	43.18	.6942		
Easy-going vs. worrier	25	36.23	.1481		
Active vs. inactive	**27**	**35.53**	**.0477**	**.6090**	**.3868- .9589**
Happy vs. sad	38	40.86	.9175		

Note. Only the RRs significant at the < .05 level are reported.

Swallowing Disorders and Quality of Life

To assess the effects of a swallowing disorder on quality of life in the RA population, results from the M.D. Anderson Dysphagia Inventory (MDADI) were analyzed. These measures were associated with current swallowing disorders, current swallowing symptoms, and RA severity. Scores on the MDADI, a measure of swallowing-related quality of life, can range from 0 (poorest QOL) to 100 (best QOL). Participants' scores ranged from 30 to 100, and scores were significantly lower for those who indicated they had a current swallowing disorder ($M = 81.2$, $SD = 13.6$ vs. 92.0, $SD = 9.8$, $p < .0001$). MDADI was not significantly associated with age, sex, race, ethnicity, income, or education. Swallowing-related quality of life was significantly lower for those with 12 of the 19 swallowing symptoms, as shown in Table 12.

The SF-36 general quality of life measure was compared with current swallowing disorders and current swallowing symptoms. The two summary measures of the SF-36 are physical health and mental health. Each summary measure is associated with four subscales (Physical Health: physical function, role-physical, bodily pain, general health; and, Mental Health: vitality, social functioning, role-emotional, mental health). The raw scores from the questionnaire are coded into a 0 to 100 scale, with 100 representing the highest state of health. Average scores for each of the scale items across all participants have been reported previously, ranging from the 70s for general health, bodily pain, and energy/fatigue, to the 80s for social functioning, physical functioning, role limitations – physical health, and emotional well-being, to the 90s for role limitations – emotional stresses. The highest possible score for physical functioning is obtained by performing all types of physical activity including the most vigorous without limitations due to

Table 12. Swallowing symptoms and relation with MDADI scores

Symptom	MDADI Score		
	No Current Symptom *M* (*SD*)	Current Symptom *M* (*SD*)	*t* statistic *p* value
Take longer time to eat because of swallowing problem (*n* = 21)	**91.0 (10.6)**	**76.3 (13.2)**	**< .0001**
Difficulty swallowing liquids (*n* = 17)	**89.9 (11.2)**	**76.3 (13.2)**	**.001**
Difficulty swallowing solids (*n* = 32)	**91.5 (10.9)**	**79.3 (12.2)**	**< .0001**
Difficulty swallowing medications (*n* = 27)	88.9 (12.1)	83.3 (13.3)	.066
Gurgley or wet voice during or after eating (*n* = 10)	**88.6 (11.7)**	**75.9 (15.3)**	**.028**
Coughing, throat clearing, or choking before, during, or after eating (*n* = 30)	**90.7 (11.1)**	**80.1 (12.9)**	**.0001**
Inability to control food, liquid, or saliva in the mouth (*n* = 8)	88.0 (12.2)	79.6 (15.7)	.179
Sneezing during or after a meal (*n* = 16)	**88.7 (12.6)**	**80.3 (10.5)**	**.009**
Pain or pressure in the throat or chest during swallowing (*n* = 22)	**89.6 (11.9)**	**79.5 (12.2)**	**< .0001**
Wheezing after eating (*n* = 5)	**87.8 (12.6)**	**79.2 (10.8)**	**.002**
Food comes out of nose while eating (*n* = 1)	87.5 (12.6)	74.0 (0)	.291
A need to chew excessively in order to swallow safely (*n* = 27)	**90.4 (11.1)**	**79.3 (12.9)**	**< .0001**
Dry mouth (*n* = 52)	**91.5 (9.9)**	**83.7 (13.7)**	**.002**
Difficulty placing food in mouth (*n* = 2)	87.1 (12.7)	97.5 (3.5)	.092
Sensation of food sticking in throat (*n* = 28)	88.7 (12.4)	83.9 (12.8)	.091
Forcibly regurgitate food stuck in throat (*n* = 10)	**88.6 (12.3)**	**75.9 (10.1)**	**.003**
Avoid eating certain foods because of swallowing disorder (*n* = 16)	**89.3 (11.6)**	**77.3 (13.4)**	**.003**
Increased mucous or phlegm in throat before, during, or after eating (*n* = 17)	88.7 (11.6)	81.4 (15.9)	.087
Take smaller bites of food to swallow safely (*n* = 28)	**91.9 (10.0)**	**75.9 (11.2)**	**< .0001**

health; for role-physical is obtained by having no problems with work or other daily activities; for bodily pain is obtained by having no pain or limitations due to pain; for general health is obtained by evaluating personal health as excellent; for energy/fatigue is obtained by feeling full of pep and energy all the time; for social functioning is obtained by performing normal social activities without interference due to physical or emotional problems; for role – emotional is obtained by having no problems with work or other daily activities; and for mental health is obtained by feeling peaceful, happy, and calm all of the time.

A current swallowing disorder was significantly negatively associated with lower physical and mental quality-of-life ratings. The mean physical quality-of-life rating for those with a swallowing disorder was 42.36, compared to 55.41 for those without a swallowing disorder ($p = .0061$). Mean mental quality of life was 61.92 in those with a swallowing disorder, compared to 76.30 in those without a swallowing disorder ($p =$ 0002). Significant differences were found in seven of the eight subscales of the SF-36: physical functioning ($p = .028$), role-physical ($p = .005$), role-emotional ($p = .001$), vitality ($p = .003$), mental health ($p = .003$), social functioning ($p = .006$), and general health ($p = .017$).

To assess the relationship between daily, overall health, and the potential effects on swallowing, RA severity, and quality of life, an additional single-question measure was used. The variable about "how you feel, overall, on a daily basis" was independently significantly associated with 2 swallowing symptoms: coughing, throat clearing, or choking before, during, or after eating ($p = .011$), and taking smaller bites of food in order to swallow safely ($p = .035$).

Participants were asked to rate the overall severity of their autoimmune condition, from the following: no problem, mild problem, moderate problem, or severe problem. This overall severity rating was used to assess prevalence of symptoms according to disease severity, as shown in Table 13. Five of the 19 swallowing symptoms were significantly associated with disease severity: taking a longer time to eat because of swallowing problem ($p = 0.34$), coughing, throat clearing, or choking before, during, or after eating ($p = .0002$), dry mouth ($p = .033$), increased mucous or phlegm in throat

Table 13. Overall self-rated disease severity and presence of current symptoms

	Overall Severity of Autoimmune Condition				
Current Symptom	**No problem** ***n***	**Mild** ***n***	**Moderate** ***n***	**Severe** ***n***	χ^2 ***p* value**
Take longer time to eat because of swallowing problem (*n* = 21)	**0**	**2**	**12**	**7**	**.034**
Difficulty swallowing liquids (*n* = 17)	0	1	11	5	.059
Difficulty swallowing solids (*n* = 32)	1	3	19	9	.058
Difficulty swallowing medications (*n* = 27)	0	6	15	6	.524
Gurgley or wet voice during or after eating (*n* = 10)	0	0	8	2	.229
Coughing, throat clearing, or choking before, during, or after eating (*n* = 30)	**0**	**1**	**17**	**12**	**.0002**
Inability to control food, liquid, or saliva in the mouth (*n* = 8)	0	1	6	1	.758
Sneezing during or after a meal (*n* = 16)	0	0	13	3	.132
Pain or pressure in the throat or chest during swallowing (*n* = 22)	1	2	14	5	.387
Wheezing after eating (*n* = 5)	0	0	3	2	.158
Food comes out of nose while eating (*n* = 1)	0	0	1	0	.917
A need to chew excessively in order to swallow safely (*n* = 27)	0	4	15	8	.073
Dry mouth (*n* = 52)	**3**	**5**	**29**	**15**	**.033**
Difficulty placing food in mouth (*n* = 2)	0	1	1	0	.455
Sensation of food sticking in throat (*n* = 28)	1	4	18	5	.713
Forcibly regurgitate food stuck in throat (*n* = 10)	0	1	8	1	.728
Avoid eating certain foods because of swallowing disorder (*n* = 16)	0	4	7	5	.42
Increased mucous or phlegm in throat before, during, or after eating (*n* = 17)	**0**	**0**	**10**	**7**	**.004**
Take smaller bites of food to swallow safely (*n* = 28)	**0**	**2**	**17**	**9**	**.008**

before, during, or after eating ($p = .004$), and taking smaller bites of food in order to swallow safely ($p = .008$).

Nineteen participants of the 41 (46%) with a current swallowing disorder had ever sought help for their swallowing problem. Seeking professional help to treat a swallowing problem was not significantly associated with any assessed factors. Of those who sought help, 13 saw a physician, 2 saw a speech-language pathologist, 2 saw another provider, 1 saw a physician and a dietitian, and 1 saw a speech-language pathologist, a physician, and an allergist. Fourteen of the 19 who sought help (74%), indicated that it helped their swallowing.

Of those who had ever had a voice disorder, 19 (54%) also had a current swallowing disorder. Overall, 19 (19%) of RA participants had both a current voice disorder and a current swallowing disorder. Incidence of both voice and swallowing problems was associated with a higher disease severity score, as shown in Table 14. The high incidence of comorbidity of voice and swallowing disorders indicates that laryngeal involvement of RA may affect multiple domains, and thus have a more significant impact on quality of life than has been understood historically.

Discussion

The results of this study suggest that swallowing disorders are common among participants with RA, and certainly more prevalent as compared to the general population. Of the 100 participants surveyed, 40% reported a current swallowing disorder compared to 12 to 13% in the general population. Of the 40 participants who indicated a current swallowing disorder, 36 (82%) reported that their voice problem

Table 14. Voice and swallowing comorbidities related to V-RQOL and RAPS

Current Voice Problem	Current Swallowing Problem	V-RQOL *M (SD)*	RAPS *M (SD)*
No	No	93.2 (8.7)	55.3 (40.7)
Yes	No	88.9 (12.1)	64.1 (40.6)
No	Yes	83.8 (12.7)	75.2 (55.3)
Yes	Yes	78.2 (14.3)	76.2 (39.8)

began gradually, and 37 reported it as a chronic problem, lasting more than 4 weeks in duration. Over half of the swallowing disorders were longstanding, with most participants' symptoms for at least 4 years.

From a long list of potential comorbid medical conditions assessed, only thyroid problems and reflux were significantly associated with a current swallowing disorder. Thyroid surgeries are known to frequently result in unilateral vocal fold paralysis (Naraynsingh, Cawich, Maharaj, & Dan, 2014), which could impact swallowing, but head and neck surgeries were not significantly associated with a swallowing disorder. Further research should be done to explore the relationship between swallowing disorders and thyroid problems. Reflux is known to be significantly associated with dysphagia (Locke, Talley, Fett, Zinsmeister, & Melton, 1997). However, there was no significant association between frequent use of refluxogenic foods (e.g., spicy foods or caffeine) and a current swallowing disorder. Additionally, a swallowing disorder was significantly more common among those who often/constantly experienced tension in their shoulders or abdomen, among those who currently participated in public speaking, and among those who had experienced voice problems associated with their job. Interestingly, there was no significant association between use of tobacco products for a year or longer, but there

was an association in those with current exposure to secondary tobacco smoke. Another interesting finding was a significant association between past exposure to dust, and among those who were physically inactive versus active. Dust is a laryngeal irritant, which may expose laryngeal structures to potential damage and may contribute to structural or compensatory voice dysfunction. However, other common irritants, such as exposure to tobacco smoke, postnasal drip, cleaning products, and other irritants, were not significantly associated with reporting a swallowing disorder.

Length of time with RA was not significantly associated with prevalence of a current swallowing disorder; however, severity of RA approached significance ($p = .08$). It is possible that given a larger sample of RA participants, severity would have been more significantly associated with presence of a swallowing disorder. There was not a significant relationship between the frequency of comorbid autoimmune conditions and a current swallowing disorder. This may be related to the relatively small number of participants who were identified as having a second autoimmune condition, which may have attenuated our ability to detect significant difference. It is also possible that some comorbid autoimmune conditions, such as Sjögren's Syndrome (SS), were present but not yet diagnosed in some participants of the study. For instance, the large number of participants reporting dry mouth may be an indicator, as that is a frequent symptom of SS. A concurrent study (Pierce, 2014) showed SS to have a high incidence of swallowing disorders as compared to the general population (64%). As these autoimmune conditions frequently coexist, it is possible that some participants had an undiagnosed condition.

Effects of Swallowing Symptoms and Disorders on Quality of Life in RA

Participants in our study reported high rates of undesirable swallowing disorders and symptoms, which were associated with adverse effects on quality of life. Review of the MDADI results revealed that swallowing disorders associated with RA produced reductions in swallowing-related quality of life. Mean swallowing quality of life was significantly reduced for those with a current swallowing disorder ($M = 81.2$, $SD = 13.6$) compared to those without a current swallowing disorder ($M = 92.0$, $SD = 9.8$) ($p < .0001$). As with the presence of voice disorders, the finding that severity of RA was not associated with presence of a current swallowing disorder may again be a result of the RAPS assessing management of the disease and presence of pain, rather than presence of the autoimmune condition, or may show that presence of the autoimmune condition rather than activity is correlated with increased risk for a swallowing disorder. As the association between RA severity and presence of a swallowing disorder approached significance, however, it is also possible that, given a larger sample, we would see a more significant association between these two variables.

The SF-36 general health quality of life measure also revealed important findings. Those who reported a swallowing disorder reported reductions in seven of the eight subscales of the SF-36. This indicates significant effects on both mental and physical health. Only bodily pain was not significantly negatively reduced. Lack of effect on bodily pain may be due to presence of RA already affecting that particular measure on participants in the study. Many participants experienced significant pain as a result of their RA, and any pain/discomfort associated with a swallowing disorder may be less prominent as a result. The additional quality of life variable, "how do you feel, overall,

on a daily basis" was significantly associated with coughing, throat clearing, or choking before, during, or after eating, and taking small bites in order to swallow safely.

Although 41% of participants reported a current swallowing disorder, only 19 of those (46%) had ever sought professional help to treat the disorder. One possible explanation for this low rate of seeking treatment may be limited education regarding prevalence of and treatment for swallowing disorders in the RA population, as well as limited treatment options. Another possibility is that individuals with RA may be more concerned with more prominent symptoms of RA than with swallowing problems. It is clear, however, that swallowing disorders are a common problem within this population, and that these problems have a significant impact on quality of life. More research needs to be undertaken to better understand the nature of the swallowing disorders within this population.

Comparisons with the Extant Literature

In reviewing the extant literature in the area of swallowing disorders in RA, the studies critiqued in Table 1 could not be directly compared to the current study primarily due to methodology differences, but also due to differing numbers of participants with RA and/or differences in definition of a swallowing disorder. Because of these reasons, general comparisons were made. It also seems that the majority of studies done on laryngeal involvement of RA focus on voice rather than swallowing.

Geterud et al. (1991) reported that dysphagia was experienced by 28% of participants in the study comprised of 29 RA participants compared to 30 controls. This study also reported that dysphagia was associated with disease severity, which differs

from the current study, which found no association between RA severity and presence of a swallowing disorder. Severity did, however, seem to be associated with presence of swallowing symptoms. The current study found a higher prevalence of swallowing disorders within the RA population, with 41% reporting a current swallowing problem. Another interesting difference between the study conducted by Geterud et al. (1991) and the current study was the lack of separation of autoimmune conditions in the latter. Participants with both RA and Sjogren's Syndrome were included, which could inflate prevalence of swallowing disorders within that group, as swallowing disorders have been found to be highly present in the SS population (Pierce, 2014). The higher prevalence of swallowing disorders in the current study suggests that either RA is more highly associated with swallowing disorders than past studies have found, or the possibility that participants in the current study may have also had undiagnosed secondary autoimmune conditions, such as SS, that contribute to these symptoms. The high rate of dryness reported in the current study may support this possibility, as this is one of the most common symptoms in SS.

While few past studies have focused on the association between swallowing disorders and presence of RA, several have examined the involvement of RA in the larynx, particularly in the cricoarytenoid joint. Cricoarytenoid joint involvement could result in voice, swallowing, and breathing symptoms, as the cricoarytenoid joint plays a crucial role in movement of the vocal folds, which can occur during each of these activities. Lofgren and Montgomery (1962) used external palpation and indirect laryngoscopy to determine involvement of the cricoarytenoid joint, and found involvement in 26% of 100 RA participants. Gomez-Puerta et al. (2013) reported that no

cricoarytenoid joint impairment was found but that pharyngeal-laryngeal reflux was found in 64% of participants. The current study did find reflux to be associated with swallowing disorders. However, only 30% of study participants reported reflux, which is less than half the reported prevalence in the Gomez-Puerta et al. study.

In spite of differences in reported prevalence among the current study and past studies done, it is clear that swallowing disorders and symptoms are more prevalent among those within the RA population. It is also clear that these disorders and symptoms have a significant adverse effect on quality of life.

CONCLUSION

This study represents the largest epidemiological investigation undertaken to assess prevalence, risk and protective factors, and socioemotional effects of voice and swallowing disorders in RA. These self-reported data not only provide compelling evidence regarding the prevalence of current voice and swallowing disorders among individuals with Rheumatoid Arthritis, but also confirm the adverse effects of these disorders on quality of life. More than half (54%) of RA participants that reported a current voice disorder also reported a current swallowing disorder. The high incidence of comorbidity of voice and swallowing disorders indicates that laryngeal involvement of RA may affect multiple domains, and thus have a more significant impact on quality of life than has been understood historically. In the future, a large random sample of individuals with rheumatoid arthritis should be surveyed to ensure proportionate representation across age, sex, and ethnicity and should assess additional risk factors that might contribute to vulnerability to these disorders, as well as best treatments for individuals within the RA population with these disorders.

APPENDIX

EPIDEMIOLOGY OF VOICE AND SWALLOWING DISORDERS IN AUTOIMMUNE DISEASES: A PILOT STUDY

Epidemiology of Voice and Swallowing Disorders in Autoimmune Diseases: A Pilot Study

Questionnaire

Date: _____ START TIME __ __ : __ __ am/pm Survey administrator: _____

To start, I have a few questions about you.

1. What is your date of birth?

   ___ / ___ / ___
   Mo. Day Yr.

2. How many years of schooling have you completed including any college, vocational, or technical training?

   _____ **[ACTUAL # OF YEARS]**

   12 = High School (includes GED)
   14 = Associate Degree
   16 = B.A., B.S.
   18 = M.A., M.S.
   20 = Ph.D., M.D., J.D., etc.

3. a. What is your race or ethnicity? Are you …(read list)
   1 = White,
   2 = Black or African American,
   3 = Native Hawaiian or Pacific Islander,
   4 = Asian,
   5 = Native American or Alaska Native, or
   6 = Hispanic
   7 = Something else? (Specify: _____)

b. Are you Hispanic or of Spanish origin?

1 = Yes
0 = No

4. Which of the following categories best describes your current household yearly gross income (before taxes for everyone who lives with you)? …

1 = Under $20,000,
2 = From $20,000 to $40,000,
3 = From $40,000 to $60,000, or
4 = More than $60,000?
5 = DON'T KNOW
6 = PREFER TO NOT ANSWER

This first section of the interview relates to your health and medical history during your entire life.

5. a. During your entire life, have you ever had…

1 = Yes **(IF YES, CONTINUE 5b-5e)**
0 = No **(GO TO NEXT MEDICAL CONDITION)**
7 = Don't Know
9 = Refused to answer

b. What year did you first have (this condition)?

— — — —

c. Are you currently taking medications for this condition?

1 = Yes
0 = No

d. In what year did you first start taking this medication?

Medical Condition	**a. Ever had**				**b. First Time**	**c. Currently taking**		**d. Year started**
	Yes	No	DK	Ref	Year	Yes	No	
Arthritis?	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Sjogren's Syndrome? Rheumatoid Arthritis? Diabetes Type 1? Wegener's Granulomatosis? Scleroderma? Dermatomyositis? Polymysitis? Systemic Lupus? Mixed connective tissue? Other disease?	1	0	7	9	— — — —	1	0	— — — —

Medical Condition	a. Ever had				b. First Time	c. Currently taking		d. Year started
Heart disease	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Hypertension / high blood pressure	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Circulatory problems	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Kidney problems	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Thyroid problems If YES Did you have… hyperthyroid (overactive) hypothyroid (underactive)	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Stomach or duodenal ulcer	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Esophageal reflux, such as burning, burping acid taste, or acid indigestion?	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Stroke	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Respiratory allergies? (IF YES) Are they… 1 = seasonal 2 = non-seasonal	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Pneumonia	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Emphysema	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Chronic Obstructive Pulmonary Disease or COPD?	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Bronchitis	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Asthma	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Severe neck, back, or head injury	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Chronic pain	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Cancer	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Depression or anxiety	1	0	7	9	__ __ __ __	1	0	__ __ __ __
Sleep disorder	1	0	7	9	__ __ __ __	1	0	__ __ __ __

6. On average, how many times a year do you get **(CONDITION)**?

Would you say never, less than once a year, once or twice a year, 3 to 5 times, 6 to 8 times, or more than 8 times a year?

Condition	Never	< 1	1-2	3-5	6-8	➢ 8
a. colds?	0	1	2	3	4	5
b. sinus infections?	0	1	2	3	4	5
c. sore throats?	0	1	2	3	4	5

7. Do you have post-nasal drip …

1 = Chronically,
2 = Seasonally,
3 = Occasionally with colds, or
4 = Not at all?

8. Have you ever had surgery?

1 = YES
0 = NO (if no, skip to question 9)

Surgery	Yes	No
a. Head and neck surgery	1	0
b. Chest / Thoracic surgery	1	0
c. Abdominal surgery	1	0
d. Other. Specify_____ _____	1	0

9. Did any of your surgeries or hospitalizations require you to be on a respirator / ventilator / breathing machine or trach?

   1 = YES
   0 = NO

10. **CODE SEX.** ASK IF UNSURE: Are you…

    0 = Male or **(GO TO Q12)**
    1 = Female?

11. [FOR WOMEN ONLY]

a. Have you stopped having menstrual periods? **(If NO, go to Q 12)**

b. How many years ago did you stop menstruating?

   1-2 years = 0
   3-5 years = 1
   6-10 years = 2
   10+ years = 3

c. Are you taking estrogen replacement therapy?

   1 = YES
   0 = NO **(IF NO, GO TO 12)**

d. How long have you been taking replacement therapy?

   1-2 years = 0
   3-5 years = 1
   6-10 years = 2
   10+ years = 3

12. Now we have a few questions about some of your personal habits including cigarette smoking, other tobacco use, and the use of alcohol.

a. Have you ever used any tobacco products for a year or longer?

1 = Yes
0 = No **(GO TO Q 13)**

b. Have you ever (smoked/used) **[TYPE]** for a year or longer?

	Yes	No
a. Cigarettes	1	0
b. Cigars	1	0
c. Pipes	1	0
d. Chewing tobacco	1	0

c. What year did you first start (smoking/chewing)?

— — — —

d. Do you still (smoke/chew)?

1 = Yes **(GO TO f)**
0 = No

e. In what year did you stop (smoking/chewing)?

— — — —

f. On average, how many (cigarettes/cigars/pipefuls/pinches) (do/did) you (smoke/use) a day?

_____

13. a. At any year in your life, did you drink an average of one or more alcoholic beverages a week?

1 = Yes
0 = No **(GO TO Q14)**

b. How old were you when you first started drinking alcoholic beverages regularly?

__ __ years

c. Do you still drink? **[THIS MEANS ANY AMOUNT OF ALCOHOL]**

1 = Yes **(GO TO e)**
0 = No

d. What year did you stop drinking?

__ __ __ __

e. On average, how many drinks do/did you drink in a week?
_____ # drinks

14. a. Have you ever used recreational drugs?

1 = Yes
0 = No (IF NO, GO TO 15)

b. Have you ever used (TYPE) for a year or longer?

a. Marijuana
b. Heroine
c. Cocaine
d. LSD
e. Other. Specify _____

c. How old were you when you first started using recreational drugs regularly?

__ __ years

d. Do you still use recreational drugs?

1 = Yes **(GO TO f)**
0 = No

e. What year did you stop using recreational drugs?

— — — —

f. On average, how many times do / did you use recreational drugs in a week?

_____ # of times

15. How often do you use / partake of the following items? (read "constantly, often…never")

Activity	Constantly	Often	Occasionally	Rarely	Never
a. Coffee	5	4	3	2	1
b. Tea	5	4	3	2	1
c. Colas	5	4	3	2	1
d. Chocolate	5	4	3	2	1
e. Dairy Products	5	4	3	2	1
f. Mint Products	5	4	3	2	1
g. Acidic Foods	5	4	3	2	1
h. Spicy Foods	5	4	3	2	1
i. Water	5	4	3	2	1

16. How often do you experience tension in the following areas? (read "constantly, often…never")

Activity	Constantly	Often	Occasionally	Rarely	Never
a. Neck / Throat	5	4	3	2	1
b. Jaw	5	4	3	2	1
c. Shoulders	5	4	3	2	1
d. Abdomen	5	4	3	2	1

17. Now I would like to ask you some questions about your voice. For the purpose of this study, we consider a voice problem to be any time your voice does not work, perform, or sound as you feel it normally should, so that it interferes with communication.

a. Do you currently have a voice problem like this?

1 = Yes (continue to 17b below)
0 = No (skip to 18)

b. Did the problem begin suddenly or gradually?

1 = Suddenly
0 = Gradually

c. Has this problem lasted for more than 4 weeks?

1 = Yes
0 = No (IF NO – GO TO 18)

d. When did you first notice the problem?

1 = 1-6 months ago
2 = 7-12 months ago
3 = 1-3 years ago
4 = 4-9 years ago
5 = 10+ years ago

18. a. Have you ever had a voice problem like this in the past?

1 = Yes
0 = No **(GO TO Q 19a)**

b. Approximately what year did you first notice that you had a voice problem?

— — — —

c. Did this problem last for 4 weeks or more?

1 = Yes **(CHRONIC)**
0 = No **(ACUTE)**

d. Did the problem begin gradually or suddenly?

1 = Gradually
2 = Suddenly

e. Have you had any voice problems since that time?

1 = Yes
0 = No **(GO TO Q 19)**

f. Have your voice problems been …

1 = continual, or
0 = off and on?

g. Have you ever seen a doctor or speech pathologist about any type of voice problem?

1 = Yes
0 = No **(GO TO Q 19)**

h. What year did you first see a doctor or speech pathologist about a voice problem?

— — — —

i. What was the problem?

_____

19. Do you have a family history of any type of voice problem?

1 = Yes
0 = No

20. Now, I will read a list of voice symptoms. For each one, please tell me if you have ever had that symptom.

a. Have you ever had (SYMPTOM)?

1 = Yes
0 = No **(GO TO NEXT SYMPTOM)**

b. Do you have this symptom currently?

1 = Yes
0 = No

c. How often do you have this (symptom)? Would you say …

1 = daily,
2 = weekly,
3 = monthly,
4 = several times a year, or
5 = yearly or less?

d. Do you think this (symptom) is the result of your job?

1 = Yes
0 = No

SYMPTOM	a. Past		b. Current		c. Frequency					d. Job	
	Yes	No	Yes	No	Dy	Wk	Mn	Sev	Yr	Yes	No
aa. Hoarseness?	1	0	1	0	1	2	3	4	5	1	0
ab. Your voice tire or change quality after using it for even a short time?	1	0	1	0	1	2	3	4	5	1	0
ac. Trouble speaking or singing softly?	1	0	1	0	1	2	3	4	5	1	0
ad. Difficulty projecting your voice?	1	0	1	0	1	2	3	4	5	1	0
ae. A loss of singing range?	1	0	1	0	1	2	3	4	5	1	0
af. Discomfort while using your voice?	1	0	1	0	1	2	3	4	5	1	0
ag. A monotone voice (monopitch)?	1	0	1	0	1	2	3	4	5	1	0

ah. To make an effort to talk?	1	0	1	0	1	2	3	4	5	1	0
ai. Chronic dryness in your throat?	1	0	1	0	1	2	3	4	5	1	0
aj. Wet, gurgley voice quality	1	0	1	0	1	2	3	4	5	1	0
ak. Chronic soreness in your throat?	1	0	1	0	1	2	3	4	5	1	0
al. To frequently clear your throat?	1	0	1	0	1	2	3	4	5	1	0
am. A bitter or acid taste?	1	0	1	0	1	2	3	4	5	1	0
an. Wobbly or shaky voice?	1	0	1	0	1	2	3	4	5	1	0
ao. An “airy” or “breathy” voice?	1	0	1	0	1	2	3	4	5	1	0

21. Next, I will read a list of activities. For each one, please tell me whether you do this constantly, often, occasionally, rarely or never during an average day.

How frequently do you (**ACTIVITY)** during an average day? Would you say constantly, often, occasionally, rarely or never?**Activity**	**Constantly**	**Often**	**Occasionally**	**Rarely**	**Never**
a. Talk	5	4	3	2	1
b. Talk quietly	5	4	3	2	1
c. Whisper	5	4	3	2	1
d. Talk loudly	5	4	3	2	1
e. Sing	5	4	3	2	1
f. Shout, yell, or cheer	5	4	3	2	1
g. Clear your throat	5	4	3	2	1
h. Laugh	5	4	3	2	1
i. Cough	5	4	3	2	1

22. Some people use / have used their voices for other activities.

    a. Do you currently participate in (ACTIVITY)?

        1 = YES
        0 = NO

b. In the past, have you participated in (ACTIVITY)?

1 = YES
0 = NO

Activity	Current		Past	
	Yes	No	Yes	No
aa. choral singing	1	0	1	0
ab. singing at church	1	0	1	0
ac. solo singing	1	0	1	0
ad. stage acting	1	0	1	0
ae. public speaking	1	0	1	0
af. volunteer activities	1	0	1	0

23. Now we would like some information about your work history. Some occupations require extensive voice use such as sales, teaching, broadcasting, clergy, telephone operator, or receptionist.

a. Are / were you ever employed in a job that required you to talk a lot on a daily basis?

1 = Yes
0 = No (IF NO, GO TO 24)

b. How many years have you been / were you employed in this type of job?

1 = 0 – 9
2 = 10 – 19
3 = 20 – 29
4 = 30 – 39
5 = 40+

c. What is / was your job title? _____

d. What are / were your activities on this job?_____

_____

e.. Do / Did you experience any voice problems with this job?

1 = YES
0 = NO (IF NO, GO TO h)

f.. How long did the problem last? Would you say…

1 = A few days
2 = A few weeks
3 = A few months, or
4 = A year or more

g. Would you say…

1 = your voice **limits / limited** your ability to do certain tasks in this job?
2 = your voice **makes / made you unable** to do certain tasks
3 = your voice **does not / did not affect** your ability to do various tasks

h. Did you ever change (IF EMPLOYED or feel you need to change) your occupation or job because of your voice?

1 = YES
0 = NO

i. Did you have to retire or take disability due to your voice problem?

1 = YES
0 = NO

24. a. Have you ever sought professional help to improve your voice in any way?

1 = Yes
0 = No **(GO TO Q 25)**

b. Did you see … **[CIRCLE ALL THAT APPLY]**

1 = a speech or language pathologist,
2 = a physician,
3 = a singing or acting teacher or coach, or
4 = someone else? Specify_____

c. Did it help you?

1 = Yes
0 = No

25. We are interested in whether you have ever been exposed to any of the following?

a. Are you currently exposed to (ITEM)?

1 = YES
0 = NO

b. Have you ever been exposed to (ITEM)?

1 = YES
0 = NO

Exposure	Current		Past	
	Yes	No	Yes	No
aa. Excess Dust	1	0	1	0
ab. Fumes from cleaning products	1	0	1	0
ac. Secondary tobacco smoke	1	0	1	0
ad. Dry air	1	0	1	0
ae. Other. Specify_____ _____	1	0	1	0

26. I will now ask you 10 questions about problems you may be having with your voice. Each question will ask you to rate the severity of the problem for you. To determine how "bad" it is, think of both how often the problem occurs and how severe it is when it happens. Rate each question on a 5-point scale below, with "5" being the worst possible. Your answers should be based on your average voice quality over the past 2 weeks or so. (Read the 5-point scale when completing this section.)

1 = None, not a problem
2 = A small amount
3 = A moderate (medium) amount
4 = Frequently
5 = As bad as it can be

Read "Because of your voice" prior to each question; (give options "none, small amount…as bad as can be" for each question)

	None	Small Amt.	Mod. Amt.	Freq.	As bad as can be
a. Do you have trouble speaking loudly or being heard in noisy situations?	1	2	3	4	5
b. Do you run out of air and need to take frequent breaths when talking?	1	2	3	4	5
c. You do not know what will come out when you begin speaking?	1	2	3	4	5
d. Do you get anxious or frustrated?	1	2	3	4	5
e. Do you get depressed?	1	2	3	4	5

	None	Small Amt.	Mod. Amt.	Freq.	As bad as can be
f. Do you have trouble using the telephone?	1	2	3	4	5
g. Do you have trouble doing your job or practicing your profession? (Indicate if not applicable ____NA)	1	2	3	4	5
h. Do you avoid going out socially?	1	2	3	4	5
i. Do you have to repeat yourself to be understood?	1	2	3	4	5
j. Have you become less outgoing?	1	2	3	4	5

Now, I would like to ask you some questions about your ability to swallow. For the purpose of this study we consider a swallowing problem to be anytime when you experience difficulty moving food or liquid from your mouth to your stomach or anytime you experience choking or frequent throat clearing during or following mealtime.

27a. Do you currently have a swallowing problem like this?

1 = Yes
0 = No (Skip to 28a)

b. Did the swallowing problem begin suddenly or gradually?

1 = suddenly
0 = gradually

c. Has this swallowing problem lasted for more than 4 weeks?

1 = Yes
0 = No (IF NO, GO TO 28)

d. When did you first notice that you have this swallowing problem?

1 = 1-6 months
2 = 7-12 months
3 = 1-3 years
4 = 4-9 years
5 = 10+ years

e. Did your swallowing problem begin with a reaction to medicine:

1 = Yes
0 = No

f. Did your swallowing problem begin following an illness?

1 = Yes
0 = No

g. Did your swallowing problem begin following surgery?

1 = Yes
0 = No

28a. Have you ever had a swallowing problem like this in the past?

1 = Yes
0 = No (Skip to 29)

28b. Approximately what year did you notice that you had this problem?

— — — —

29. Have you ever had?

a. A feeding tube

1 = Yes
0 = No

b. A need to use nutritional supplements (e.g. Ensure, Boost) to make sure that you are taking in enough calories each day?

1 = Yes
0 = NO

30. Now, I will read a list of swallowing symptoms. For each one, please tell me if you have ever had that symptom.

a. Have you ever had (SYMPTOM)?

1 = Yes
0 = No **(GO TO NEXT SYMPTOM)**

b. Do you have (SYMPTOM) currently?

1 = Yes
0 = No

c. How often do you have (SYMPTOM)? Would you say…

1 = daily,
2 = weekly,
3 = monthly,
4 = several times a year, or
5 = yearly or less?

SYMPTOM	a. Past		b. Current		c. Frequency				
	Yes	No	Yes	No	Dy	Wk	Mn	Sev	Yr
aa. To take a longer time to eat because of your swallowing problem?	1	0	1	0	1	2	3	4	5
ab. Difficulty swallowing liquids?	1	0	1	0	1	2	3	4	5
ac. Difficulty swallowing solids?	1	0	1	0	1	2	3	4	5
ad. Difficulty swallowing medications?	1	0	1	0	1	2	3	4	5
ae. A gurgley or wet voice during or after eating?	1	0	1	0	1	2	3	4	5
af. Coughing, throat clearing, or choking before, during or after eating?	1	0	1	0	1	2	3	4	5
ag. An inability to control food, liquid, or saliva in the mouth?	1	0	1	0	1	2	3	4	5
ah. Any sneezing during or after a meal?	1	0	1	0	1	2	3	4	5
ai. Pain or pressure in the throat or chest during swallowing?	1	0	1	0	1	2	3	4	5
aj. Wheezing after eating?	1	0	1	0	1	2	3	4	5
ak. Food come out of your nose while eating?	1	0	1	0	1	2	3	4	5
al. A need to chew excessively in order to swallow safely?	1	0	1	0	1	2	3	4	5
am. Dry mouth?	1	0	1	0	1	2	3	4	5
an. Difficulty placing food in mouth?	1	0	1	0	1	2	3	4	5

SYMPTOM	a. Past		b. Current		c. Frequency				
	Yes	No	Yes	No	Dy	Wk	Mn	Sev	Yr
ao. A sensation of food sticking in your throat?	1	0	1	0	1	2	3	4	5
ap. To forcibly regurgitate food that is stuck in your throat?	1	0	1	0	1	2	3	4	5
aq. To avoid eating certain foods because of your swallowing disorder?	1	0	1	0	1	2	3	4	5
ar. Increased mucous or phlegm in your throat before, during, or after you eat?	1	0	1	0	1	2	3	4	5
as. To take smaller bites of food in order to swallow safely.	1	0	1	0	1	2	3	4	5

31. The next few questions ask about your views of your swallowing ability. This information will help us understand how you feel about swallowing. The following statements have been made by people who have problems with their swallowing. Some of the statements may apply to you. Please listen to each statement and indicate the response which best reflects your experience in the past week. You may refer to this key as you consider your answer. (READ KEY OF 5 POSSIBLE RESPONSES)

	Strongly Agree	Agree	No Opinion	Disagree	Strongly Disagree
a. My swallowing ability limits my day-to-day activities	1	2	3	4	5
b. I am embarrassed by my eating habits.	1	2	3	4	5
c. People have difficulty cooking for me.	1	2	3	4	5
d. Swallowing is more difficult at the end of the day.	1	2	3	4	5
e. I do not feel self-conscious when I eat.	5	4	3	2	1
f. I am upset by my swallowing problem.	1	2	3	4	5
g. Swallowing takes great effort.	1	2	3	4	5
h. I do not go out because of my swallowing problem.	1	2	3	4	5
i. My swallowing difficulty has caused me to lose income?	1	2	3	4	5
j. It takes me longer to eat because of my swallowing problem.	1	2	3	4	5
k. People ask me, “Why can’t you eat that?”	1	2	3	4	5
l. Other people are irritated by my eating problem.	1	2	3	4	5
m. I cough when I try to drink liquids.	1	2	3	4	5

	Strongly Agree	Agree	No Opinion	Disagree	Strongly Disagree
n. My swallowing problems limit my social and personal life.	1	2	3	4	5
o. I feel free to go out to eat with my friends, neighbors, and relatives.	5	4	3	2	1
p. I limit my food intake because of my swallowing difficulty.	1	2	3	4	5
q. I cannot maintain my weight because of my swallowing problem.	1	2	3	4	5
r. I have low self-esteem because of my swallowing problem.	1	2	3	4	5
s. I feel that I am swallowing a huge amount of food.	1	2	3	4	5
t. I feel excluded because of my eating habits.	1	2	3	4	5

32. Do you have a family history of any type of swallowing problem?

1 = Yes
0 = No
DK= Don't know

33. a. Have you ever sought professional help to assess or treat your swallowing problem in any way?

1 = Yes
0 = No **(GO TO Q 34)**

b. Did you see … **[CIRCLE ALL THAT APPLY]**

1 = a speech or language pathologist,
2 = a physician,
3 = a dietician, or
4 = someone else? Specify_____

c. Did it help you?

1 = Yes
0 = No

d. Did you ever receive a diagnosis related to your swallowing?

1 = Yes
0 = No **(Go To Q 34)**

e. What was the diagnosis you received? _____

34. a. Do you live alone?

1 = Yes (IF YES, GO TO 35)
0 = No

b. How many people (including you) live in your home? ____ (insert #)

35. a. Do you have a hearing loss?

1 = Yes
0 = No (IF NO, GO TO 36)

b. Do you wear hearing aids on a regular basis?

1 = Yes
0 = No

36. a. Do you exercise?

1 = Yes
0 = No (GO TO 37)

b. How often do you exercise?

1 = 1-2 X week
2 = 3-4 X week
3 = 5+ X week

37. Overall, how do you feel on a daily basis?

1 = excellent
2 = good
3 = fair
4 = poor

38. Would you describe yourself as …

a. Quiet or talkative

1 = Quiet
0 = Talkative

b. Easy-going or a worrier

1 = Easy-going
0 = Worrier

c. Active or inactive

1 = Active
0 = Inactive

d. Happy or sad

1 = Happy
0 = Sad

39. What is your religious preference?

1 = Protestant
2 = Catholic
3 = LDS/Mormon
4 = Jewish
5 = Other
6 = No Religion
7 = Prefer not to answer

40. Now I would like to ask you some questions about your speech. For the purpose of this study, we consider a speech problem to be any time when you experience difficulty with speech production (including slurred speech or imprecise sound production/articulation) so that it interferes with communication.

a. Do you currently have a speech problem like this?

1 = Yes (continue to 40b below)
0 = No (skip to 41)

b. Did the problem begin suddenly or gradually?

1 = Suddenly
0 = Gradually

c. Has this problem lasted for more than 4 weeks?

1 = Yes
0 = No (IF NO – GO TO 41)

d. When did you first notice the problem?

1 = 1-6 months ago
2 = 7-12 months ago
3 = 1-3 years ago
4 = 4-9 years ago
5 = 10+ years ago

41. a. Have you ever had a speech problem like this in the past?

1 = Yes
0 = No **(GO TO Q 42)**

b. Approximately what year did you first notice that you had a speech problem?

— — — —

c. Did this problem last for 4 weeks or more?

1 = Yes **(CHRONIC)**
0 = No **(ACUTE)**

d. Did the problem begin gradually or suddenly?

1 = Gradually
2 = Suddenly

e. Have you had any speech problems since that time?

1 = Yes
0 = No **(GO TO Q 42)**

f. Have your speech problems been …

1 = continual, or
0 = off and on?

g. Have you ever seen a doctor or speech pathologist about any type of speech problem?

1 = Yes
0 = No **(GO TO Q 42)**

h. What year did you first see a doctor or speech pathologist about a speech problem?

— — — —

i. What was the problem?

_____

42. Do you have a family history of any type of speech problem?

1 = Yes
0 = No

43. *I would like to ask you a few more questions about your general health.* (READ NUMERIC CHOICES)
(Medical Outcomes Study: 36-Item Short Form Survey Instrument (RAND 36-Item Health Survey 1.0 Questionnaire Items)

1. In general, would you say your health is:	
Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

2. **Compared to one year ago**, how would your rate your health in general **now**?	
Much better now than one year ago	1
Somewhat better now than one year ago	2
About the same	3
Somewhat worse now than one year ago	4
Much worse now than one year ago	5

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much? **(Circle One Number on Each Line)**

	Yes, Limited a Lot	Yes, Limited a Little	No, Not limited at All
3. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	[1]	[2]	[3]
4. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	[1]	[2]	[3]
5. Lifting or carrying groceries	[1]	[2]	[3]
6. Climbing **several** flights of stairs	[1]	[2]	[3]
7. Climbing **one** flight of stairs	[1]	[2]	[3]
8. Bending, kneeling, or stooping	[1]	[2]	[3]
	Yes, Limited a Lot	Yes, Limited a Little	No, Not limited at All
9. Walking **more than a mile**	[1]	[2]	[3]
10. Walking **several blocks**	[1]	[2]	[3]
11. Walking **one block**	[1]	[2]	[3]
12. Bathing or dressing yourself	[1]	[2]	[3]

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

(Circle One Number on Each Line)

	Yes	No
13. Cut down the amount of time you spent on work or other activities	1	2
14. **Accomplished less** than you would like	1	2
15. Were limited in the **kind** of work or other activities	1	2
16. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2

During the **past 4 weeks,** have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

(Circle One Number on Each Line)

	Yes	No
17. Cut down the **amount of time** you spent on work or other activities	1	2
18. **Accomplished less** than you would like	1	2
19. Didn't do work or other activities as **carefully** as usual	1	2

20. During the **past 4 weeks,** to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?
(Circle One Number)

Not at all = 1
Slightly = 2
Moderately = 3
Quite a bit = 4
Extremely = 5

21. How much **bodily** pain have you had during the **past 4 weeks**?
(Circle One Number)

None = 1
Very mild = 2
Mild = 3
Moderate = 4
Severe = 5
Very severe = 6

22. During the **past 4 weeks,** how much did **pain** interfere with your normal work (including both work outside the home and housework)?
(Circle One Number)

Not at all = 1
A little bit = 2
Moderately = 3
Quite a bit = 4
Extremely = 5

These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks** . . .

(Circle One Number on Each Line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
23. Did you feel full of pep?	1	2	3	4	5	6
24. Have you been a very nervous person?	1	2	3	4	5	6
25. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
26. Have you felt calm and peaceful?	1	2	3	4	5	6
27. Did you have a lot of energy?	1	2	3	4	5	6
28. Have you felt downhearted and blue?	1	2	3	4	5	6
29. Did you feel worn out?	1	2	3	4	5	6
30. Have you been a happy person?	1	2	3	4	5	6
31. Did you feel tired?	1	2	3	4	5	6

32. During the **past 4 weeks,** how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

(Circle One Number)

All of the time = 1
Most of the time = 2
Some of the time = 3
A little of the time = 4
None of the time = 5

How TRUE or FALSE is each of the following statements for you.

(Circle One Number on Each Line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
33. I seem to get sick a little easier than other people	1	2	3	4	5
34. I am as healthy as anybody I know	1	2	3	4	5
35. I expect my health to get worse	1	2	3	4	5
36. My health is excellent	1	2	3	4	5

44. Lastly, we would like to ask you a few questions about your autoimmune condition. How would you rate the overall severity of your autoimmune condition (Sjogren's Syndrome, Rheumatoid Arthritis, Diabetes Type 1, Wegener's Granulomatosis, Scleroderma, Dermatomyositis, Polymyositis, Systemic Lupus)?

1 = no problem
2 = mild problem
3 = moderate problem
4 = severe problem

45. (Examiner, **circle** the diagnosis below and **administer** the appropriate Disease Severity Scale included in the **Appendix**).

1 = Sjogren's Syndrome
2 = Rheumatoid Arthritis
3 = Diabetes Type 1
4 = Wegener's Granulomatosis
5 = Scleroderma
6 = Dermatomyositis
7 = Polymysitis
8 = Systemic Lupus
9 = Mixed connective tissue disease

CLOSING:
That is all the information we need. Do you have any questions or comments about the study?

_____

_____

_____

The University of (Utah) thanks you for your time (today/this evening).

END TIME __ __ : __ __ am / pm

APPENDIX: Sjogren's Syndrome/Wegener's Granulomatosis

Sjogren's Questionnaire 1

Please consider the past 2 weeks when rating the following:

Sore Eyes

0 1 2 3 4 5 6 7

0 = No problem at all 7 = As bad as imaginable

Eye Irritation

0 1 2 3 4 5 6 7

0 = No problem at all 7 = As bad as imaginable

Poor Vision

0 1 2 3 4 5 6 7

0 = No problem at all 7 = As bad as imaginable

Difficulty Eating

0 1 2 3 4 5 6 7

0 = No problem at all 7 = As bad as imaginable

Dry Throat

0 1 2 3 4 5 6 7

0 = No problem at all 7 = As bad as imaginable

Bad Breath

0 1 2 3 4 5 6 7

0 = No problem at all 7 = As bad as imaginable

Wetting Mouth (carried fluid during day/night)

0 1 2 3 4 5 6 7

0 = No problem at all 7 = As bad as imaginable

Oral Problems

0 1 2 3 4 5 6 7

0 = No problem at all 7 = As bad as imaginable

Vaginal Dryness

0 1 2 3 4 5 6 7

0 = No problem at all 7 = As bad as imaginable

Skin Dryness

0 1 2 3 4 5 6 7

0 = No problem at all 7 = As bad as imaginable

(SSI Sicca Symptoms Inventory—Short Form, Bowman et al., 2003)

Sjogren's Questionnaire 2

Dryness

0 1 2 3 4 5 6 7 8 9 10

Limb Pain

0 1 2 3 4 5 6 7 8 9 10

Fatigue

0 1 2 3 4 5 6 7 8 9 10

(ESSPRI, Seror et al., 2011)

APPENDIX: Rheumatoid Arthritis

Rheumatoid Arthritis Pain Scale (RAPS) DIRECTIONS: The following items relate to pain and arthritis. For each item, choose one number from 0 (never) to 6 (always) to describe how you have felt in the last week.

	0 (Never)	1	2	3	4	5	6 (Always)
1. I would describe my pain as gnawing.	0	1	2	3	4	5	6
2. I would describe my pain as aching.	0	1	2	3	4	5	6
3. I would use the word exhausting to describe my pain.	0	1	2	3	4	5	6
4. I would describe my pain as annoying.	0	1	2	3	4	5	6
5. I am in constant pain.	0	1	2	3	4	5	6
6. I would describe my pain as rhythmic.	0	1	2	3	4	5	6
7. I have swelling of at least one joint.	0	1	2	3	4	5	6
8. I have morning stiffness of one hour or more.	0	1	2	3	4	5	6
9. I have pain on motion of at least one joint.	0	1	2	3	4	5	6
10. I cannot perform all the everyday tasks I normally would because of pain.	0	1	2	3	4	5	6
11. Pain interferes with my sleep.	0	1	2	3	4	5	6
12. I cannot decrease my pain by using methods other than taking extra medication.	0	1	2	3	4	5	6
13. I would describe my pain as burning.	0	1	2	3	4	5	6
14. I find that I guard my joints to reduce pain.	0	1	2	3	4	5	6
15. I brace myself because of the pain.	0	1	2	3	4	5	6
16. My pain is throbbing in nature.	0	1	2	3	4	5	6
17. I would describe my pain as sharp.	0	1	2	3	4	5	6
18. I would say my pain is severe.	0	1	2	3	4	5	6
19. I feel stiffness in my joints after rest.	0	1	2	3	4	5	6

20. My joints feel hot.	0	1	2	3	4	5	6
21. I feel anxious because of pain.	0	1	2	3	4	5	6
22. I would describe my pain as tingling.	0	1	2	3	4	5	6
23. I feel my pain is uncontrollable.	0	1	2	3	4	5	6
24. I feel helpless to control my pain.	0	1	2	3	4	5	6

When looking at the scale below, overall I would rate my pain as:

0	1	2	3	4	5	6	7	8	9	10
NONE									SEVERE	

APPENDIX: Diabetes Type 1

ADDQoL 19

If I did not have diabetes…

…I would enjoy my leisure activities

very much more | much more | a little more | the same | less

…My working life would be

very much better | much better | a little better | the same | worse

…Local or long distance journeys would be

Very much easier | much easier | a little easier | the same | more difficult

…My holidays would be

very much better | much better | a little better | the same | worse

…Physically I could do

very much more | much more | a little more | the same | less

…My family life would be

very much better | much better | a little better | the same | worse

…My friendships and social life would be

very much better | much better | a little better | the same | worse

…My closest personal relationship would be

very much better | much better | a little better | the same | worse

…My sex life would be
very much better much better a little better the same worse
…My physical appearance would be
very much better much better a little better the same worse
…My self confidence would be
very much greater much greater a little greater the same less
…My motivation would be
very much greater much greater a little greater the same less
…The way people in general react to me would be
very much better much better a little better the same worse
…My feelings about the future (e.g. worries, hopes) would be
very much better much better a little better the same worse
…My financial situation would be
very much better much better a little better the same worse
…My living conditions would be
very much better much better a little better the same worse
…I would have to depend on others when I do not want to
Very much less much less a little less the same more
…My freedom to eat as I wish would be
very much greater much greater a little greater the same less
…My freedom to drink as I wish (e.g. fruit juice, alcohol, sweetened hot and cold drinks) would be
very much greater much greater a little greater the same less

APPENDIX: Systemic Lupus

LupusQoL Questionnaire The following questionnaire is designed to find out how SLE affects your life. **Read** each statement and then circle theresponse, which is **closest to how you feel**. Please try to answer all the questions as honestly as you can.

How often over the last 4 weeks

1. Because of my Lupus I need help to do heavy physical jobs such as digging the garden, painting and/or decorating, moving furniture
All of the time most of the time a good bit of the time occasionally never

2. Because of my Lupus I need help to do moderate physical jobs such as vacuuming, ironing, shopping, cleaning the bathroom

All of the time most of the time a good bit of the time occasionally never

3. Because of my Lupus I need help to do light physical jobs such as cooking/preparing meals, opening jars, dusting, combing my hair or attending to personal hygiene

All of the time most of the time a good bit of the time occasionally never

4. Because of my Lupus I am unable to perform everyday tasks such as my job, childcare, housework as well as I would like to

All of the time most of the time a good bit of the time occasionally never

5. Because of my Lupus I have difficulty climbing stairs

All of the time most of the time a good bit of the time occasionally never

6. Because of my Lupus I have lost some independence and am reliant on others

All of the time most of the time a good bit of the time occasionally never

7. I have to do things at a slower pace because of my Lupus

All of the time most of the time a good bit of the time occasionally never

8. Because of my Lupus my sleep pattern is disturbed

All of the time most of the time a good bit of the time occasionally never

How often over the last 4 weeks

9. I am prevented from performing activities the way I would like to because of pain due to Lupus

All of the time most of the time a good bit of the time occasionally never

10. Because of my Lupus, the pain I experience interferes with the quality of my sleep

All of the time most of the time a good bit of the time occasionally never

11. The pain due to my Lupus is so severe that it limits my mobility

All of the time most of the time a good bit of the time occasionally never

12. Because of my Lupus I avoid planning to attend events in the future

All of the time most of the time a good bit of the time occasionally never

13. Because of the unpredictability of my Lupus I am unable to organise my life efficiently

All of the time most of the time a good bit of the time occasionally never

14. My Lupus varies from day to day which makes it difficult for me to commit myself to social arrangements

All of the time most of the time a good bit of the time occasionally never

15. Because of the pain I experience due to Lupus I am less interested in a sexual relationship

All of the time most of the time a good bit of the time occasionally never not applicable

16. Because of my Lupus I am not interested in sex

All of the time most of the time a good bit of the time occasionally never not applicable

17. I am concerned that my Lupus is stressful for those who are close to me

All of the time most of the time a good bit of the time occasionally never

18. Because of my Lupus I am concerned that I cause worry to those who are close to me

All of the time most of the time a good bit of the time occasionally never

19. Because of my Lupus I feel that I am a burden to my friends and/or family

All of the time most of the time a good bit of the time occasionally never

Over the past 4 weeks I have found my Lupus makes me

20. Resentful

All of the time most of the time a good bit of the time occasionally never

21. So fed up nothing can cheer me up

All of the time most of the time a good bit of the time occasionally never

22. Sad

All of the time most of the time a good bit of the time occasionally never

23. Anxious

All of the time most of the time a good bit of the time occasionally never

24. Worried

All of the time most of the time a good bit of the time occasionally never

25. Lacking in self-confidence

All of the time most of the time a good bit of the time occasionally never

How often over the past 4 weeks

26. My physical appearance due to Lupus interferes with my enjoyment of life

All of the time most of the time a good bit of the time occasionally never

27. Because of my Lupus, my appearance (e.g. rash, weight gain/loss) makes me avoid social situations

All of the time most of the time a good bit of the time occasionally never

28. Lupus related skin rashes make me feel less attractive

All of the time most of the time a good bit of the time occasionally never

How often over the past 4 weeks

29. The hair loss I have experienced because of my Lupus makes me feel less attractive

All of the time most of the time a good bit of the time occasionally never not applicable

30. The weight gain I have experienced because of my Lupus treatment makes me feel less attractive

All of the time most of the time a good bit of the time occasionally never not applicable

31. Because of my Lupus I cannot concentrate for long periods of time

All of the time most of the time a good bit of the time occasionally never

32. Because of my Lupus I feel worn out and sluggish

All of the time most of the time a good bit of the time occasionally never

33. Because of my Lupus I need to have early nights

All of the time most of the time a good bit of the time occasionally never

34. Because of my Lupus I am often exhausted in the morning

All of the time most of the time a good bit of the time occasionally never

APPENDIX: Scleroderma, Dermatomyositis, Polymyositis, Wegener's Granulomatosis

World Health Organization Disability Assessment Schedule II Phase 2 Field Trials – Health Services Research
36-Item Self-Administered Version

H1 How do you rate your overall health in the past 30 days?

Very good Good Moderate Bad Very Bad

This questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.Think back over the last 30 days and answer these questions thinking about how much difficulty you had doing the following activities. For each question, please circle only one response.

In the last 30 days, how much difficulty did you have in:

Understanding and communicating

D1.1 Concentrating on doing something for ten minutes?

None Mild Moderate Severe Extreme/Cannot Do

D1.2 Remembering to do important things?

None Mild Moderate Severe Extreme/Cannot Do

D1.3 Analyzing and finding solutions to problems in day to day life?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D1.4 Learning a new task, for example, learning how to get to a new place?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D1.5 Generally understanding what people say?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D1.6 Starting and maintaining a conversation?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

Getting Around
D2.1 Standing for long periods such as 30 minutes?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D2.2 Standing up from sitting down?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D2.3 Moving around inside your home?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D2.4 Getting out of your home?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D2.5 Walking a long distance such as a kilometer (or equivalent)?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

In the last 30 days, how much difficulty did you have in:

Self Care
D3.1 Washing your whole body?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D3.2 Getting dressed?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D3.3 Eating?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D3.4 Staying by yourself for a few days?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

Getting along with people
D4.1 Dealing with people you do not know?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D4.2 Maintaining a friendship?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D4.3 Getting along with people who are close to you?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D4.4 Making new friends?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D4.5 Sexual activities?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

Life activities
D5.1 Taking care of your household responsibilities?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D5.2 Doing most important household tasks well?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D5.3 Getting all the household work done that you needed to do?
None Mild Moderate Severe Extreme/Cannot Do

D5.4 Getting your household work done as quickly as needed?
None Mild Moderate Severe Extreme/Cannot Do

IF YOU WORK (PAID, NON-PAID, SELF EMPLOYED) OR GO TO SCHOOL, COMPLETE QUESTIONS D5.5-D5.8 BELOW. OTHERWISE, SKIP TO D6.1 AT THE TOP OF THE NEXT PAGE.

In the last 30 days, how much difficulty did you have in:

D5.5 Your day to day work/school?
None Mild Moderate Severe Extreme/Cannot Do

D5.6 Doing your most important work/school tasks well?
None Mild Moderate Severe Extreme/Cannot Do

D5.7 Getting all the work done that you need to do?
None Mild Moderate Severe Extreme/Cannot Do

D5.8 Getting your work done as quickly as needed?
None Mild Moderate Severe Extreme/Cannot Do

In the last 30 days:
Participation in Society

D6.1 How much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?
None Mild Moderate Severe Extreme/Cannot Do

D6.2 How much of a problem did you have because of barriers or hindrances in the world around you?
None Mild Moderate Severe Extreme/Cannot Do

D6.3 How much of a problem did you have living with dignity because of the attitudes and actions of others?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D6.4 How much time did you spend on your health condition, or its consequences?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D6.5 How much have you been emotionally affected by your health condition?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D6.6 How much has your health been a drain on the financial resources of you or your family?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D6.7 How much of a problem did your family have because of your health problems?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

D6.8 How much of a problem did you have in doing things by yourself for relaxation or pleasure?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

H2 Overall, how much did these difficulties interfere with your life?
None **Mild** **Moderate** **Severe** **Extreme/Cannot Do**

H3 Overall, in the past 30 days, how many days were these difficulties present? RECORD NUMBER OF DAYS ___/___

H4 In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition? RECORD NUMBER OF DAYS ___/___

H5: In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition? RECORD NUMBER OF DAYS___/___

REFERENCES

Abadir, W. E., & Forster, P. M. (1974). Rheumatoid vocal cord nodules. *The Journal of Laryngology and Otology, 88*, 473-8. Retrieved from http://www.jlo.co.uk/

Anderson, D. L (2001). Development of an instrument to measure pain in rheumatoid arthritis: Rheumatoid Arthritis Pain Scale (RAPS). *Arthritis Rheumatism. 45*(4), 317-23. Retrieved from http://onlinelibrary.wiley.com/doi/10.1002/1529-0131(200108)45:4%3C317::AID-ART343%3E3.0.CO;2-X/pdf

Arnett, F. C., Edworthy, S. M., Bloch D. A., McShane, D. J., Fries, J. F., Cooper, N. S.,…Hunder, G. G. (1988). The American rheumatism association 1987 revised criteria for the classification of rheumatoid arthritis. *Arthritis & Rheumatism, 31*(3), 315-24. Retrieved from http://www.rheumatology.org/publications/ar/

Behlau, M., Zambon, F., Guerrieri, & A. C., Roy, N. (2012). Epidemiology of voice disorders in teachers and nonteachers in Brazil: Prevalence and adverse effects. *Journal of Voice*, *26*(5), 665. doi:10.1016/j.jvoice.2011.09.010

Beirith, S. C., Ikino, C. M., & Pereira, I. A., (2013). Laryngeal involvement in rheumatoid arthritis. *Brazilian Journal of Otorhinolaryngology, 79* (2), 233-8. Retrieved from http://dx.doi.org/10.5935/1808-8694.20130040/

Berjawi, G., Uthman, I., Mahfoud, L., Husseini, S. T., Nassar, J., Kotobi, A., & Hamdan, A. H. (2010). Cricothyroid joint abnormalities in patients with rheumatoid arthritis. *Journal of Voice, 24*(6), 732-737. doi: 10.1016/j.jvoice.2009.06.005

Bienenstock, H., Ehrlich, G. E., & Freyburg, R. H. (1963). Rheumatoid arthritis of the cricoarytenoid joint: A clinicopathologic study. *Arthritis & Rheumatism, 6*, 48-63. Retrieved from http://www.rheumatology.org/publications/ar/

Bitter, T., Volk, G. F., Lehamnn, P., Wittekindt, C., & Guntinas-Lichius, O. (2011). Progressive hoarseness. *HNO, 59*(3), 283-285. doi: 10.1007/s00106-010-2207-6

Davis, J. M., & Matteson, E. L. (2012). My treatment approach to rheumatoid arthritis. *Mayo Clinic Proceedings, 87*(7), 659-673. doi: 10.1016/j.mayocp.2012.03.011

Erb, N., Pace, A. V., Delamere, J. P., & Kitas, G. D. (2001). Dysphagia and stridor caused by laryngeal rheumatoid arthritis. *Rheumatology, 40*, 952-953. Retrieved from http://rheumatology.oxfordjournals.org/

Fisher, B. A., Dolan, K., Hastings, L., McClinton, C., & Taylor, P. C. (2008). Prevalence of subjective voice impairment in rheumatoid arthritis. *Clinical Rheumatology, 27*, 1441-1443. doi: 10.1007/s10067-008-0994-x

Geterud, A., Bake, B., Bjelle, A., Jonsson, R., Sandberg, N., & Ejnell, H. (1991). Swallowing problems in rheumatoid arthritis. *Acta Otolaryngologica, 111*, 1153-1161. Retrieved from http://informahealthcare.com/oto

Gomez-Puerta, J. A., Cisternas, A., Hernandez, M. V., Ruiz-Esquide, V., Vilaseca, I., & Sanmarti, R. (2013). Laryngeal assessment by videolaryngostroboscopy in patients with rheumatoid arthritis. *Reumatologia Clinica 2013*. Retrieved from http://dx.doi.org/10.1016/j.reuma.2013.04.006

Groher, M. E., & Bukatman, R. (1986). The prevalence of swallowing disorders in two teaching hospitals. *Dysphagia 1*, 3-6. Retrieved from http://www.springer.com/medicine/otorhinolaryngology/journal/455

Helmick, C. G., Felson, D. T., Lawrence, R. C., Gabriel, S., Hirsh, R., Kwoh, K.,… National Arthritis Data Workgroup. (2008). Estimates of the prevalence of arthritis and other rheumatic conditions in the United States. *Arthritis & Rheumatism, 58*(1), 15–25. doi:10.1002/art.23177

Hilgert, E., Toleti, B., Kruger, K., & Nejedlo, I. (2006). Hoarseness due to bamboo nodes in patients with autoimmune diseases: A review of literature. *Journal of Voice, 22*(3), 343-350. doi: 10.1016/j.jvoice.2006.10.009

Jacobs, C. J., & Hui, R. M. (1977). Cricoarytenoid arthritis and airway obstruction in juvenile rheumatoid arthritis. *Pediatrics, 59*(2), 292-293. Retrieved from http://pediatrics.aappublications.org/

Jacobson, B. H., Johnson, A., Grywalski, C., Silbergleit, A., Jacobson, G., Benninger, M. S., & Newman, C. G. (1997). The Voice Handicap Index (VHI): Development and validation. *American Journal of Speech-Language Pathology*, *6*(3), 66-70. Retrieved from http://ajslp.asha.org/

Kumai, Y., Murakami, D., Masuda, M., & Yumoto, E. (2007). Arytenoid adduction to treat impaired adduction of the vocal fold due to rheumatoid arthritis. *Auris Nasus Larynx, 34*, 545-548. Retrieved from http://www.aurisnasuslarynx.com/

Lawry, G. V., Finerman, M. L., Hanafee, W. N., Mancuso, A. A., Fan, P., & Bluestone, R. (1984). Laryngeal involvement in rheumatoid arthritis. A clinical, laryngoscopic, and

computerized tomographic study. *Arthritis and Rheumatism, 27,* 873–882. Retrieved from http://www.rheumatology.org/publications/ar/

Lee, L. A., Fang, T. J., & Li, H. Y. (2002). Solitary plasmacytosis of the larynx in a patient with non-Hodgkin's lymphoma. *American Journal of Otolaryngology, 23*(5), 316-320. Retrieved from http://www.amjoto.com/

Lewis, C., & Shaw, K. (2008). The Rheumatoid Arthritis Pain Scale (RAPS). *Physical Therapy and Rehab Medicine, 19*(9), 8. Retrieved from http:// http://physical-therapy.advanceweb.com/Article/The-Rheumatoid-Arthritis-Pain-Scale-RAPS.aspx

Liu, Z. W., Masterson, L. M., Srouji, I. A., Musonda, P., & Scott, D. G. (2012). Voice symptoms in patients with autoimmune disease: A cross-sectional epidemiological study. *Otolaryngology-Head Neck Surgery, 147*(6), 1108-1113. doi: 10.1177/0194599812459024

Lofgren, R. H., & Montgomery, W. W. (1962). Incidence of laryngeal involvement in rheumatoid arthritis. *New England Journal of Medicine, 26*, 193–195. Retrieved from http://www.nejm.org/

Locke, G. R. III, Talley, N. J., Fett, S. L., Zinsmeister, A. R., & Melton, L. J. III, (1997). Prevalence and clinical spectrum of gastroesophageal reflux: A population-based study in Olmsted County, Minnesota. *Gastroenterology*, *112*, 1448-56. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/9136821

Mathieson, L. (2011). The evidence for laryngeal manual therapies in the treatment of muscle tension dysphonia. *Current Opinions "Otolaryngol Head Neck Surgery, 19*(3), 171-6. doi:10.1097/MOO.0b013e3283448f6c

Matrka, L., (2014). Paradoxic vocal fold movement disorder. *Otolaryngolic Clinics of North America, 47*(1), 135-46. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/24286687

Mikkelsen, W., & Duff, I. (1955). Unusual manifestations of rheumatoid nodules. *Journal-Michigan State Medical Society, 54*, 292-297. Retrieved from http://www.msms.org/AM/Template.cfm?Section=Home

Murano, E., Hosako-Naito, Y., Tayama, N., Oka, T., Miyaji, M., Kumada, M., & Niimi, S. (2001). Bamboo node: Primary vocal fold lesion as evidence of autoimmune disease. *Journal of Voice, 15*(3), 441-450. Retrieved from http://www.jvoice.org/

Naraynsingh, V., Cawich, S., Maharaj, R., & Dan, D. (2014). Retrograde thyroidectomy: A technique for visualization and preservation of the external branch of superior laryngeal nerve. *International Journal of Surgery. Case Reports, 5*(3), 122-125. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/24514007

Pierce, J. (2014). *Epidemiology of voice and swallowing disorders in Sjögren's Syndrome*. (master's thesis). University of Utah, Salt Lake City, UT, USA.

Roy, N., Merrill, R. M., Gray, S. D., & Smith, E. M. (2005). Voice disorders in the general population: Prevalence, risk factors, and occupational impact. *The Laryngoscope, 115*, 1988–1995. Retrieved from http://onlinelibrary.wiley.com/journal/10.1002/(ISSN)1531-4995

Roy, N., Stemple, J., Merrill, R. M., & Thomas, L. (2007). Dysphagia in the elderly: Preliminary evidence of prevalence, risk factors, and socioemotional effects. *Annals of Otology, Rhinology & Laryngology, 116*(11), 858-865. Retrieved from http://www.annals.com/

Sanz, L., Sistiaga, J. A., Lara, A. J., Cuende, E., Garcia-Alcantara, F., & Rivera, T. (2011). The prevalence of dysphonia, its association with immunomediated diseases and correlation with biochemical markers. *Journal of Voice, 26*(2), 148-158. doi:10.1016/j.jvoice.2011.02.003

Sheehan, N. J. (2008). Dysphagia and other manifestations of oesophageal involvement in the musculoskeletal diseases. *Rheumatology, 47*, 746-752. doi:10.1093/rheumatology/ken029

Speyer, R., Speyer, I., & Heijnen, M. A. (2008). Prevalence and relative risk of dysphonia in rheumatoid arthritis. *Journal of Voice, 22*(2), 232-237. Retrieved from http://www.jvoice.org/

Strietzel, F. P., Lafaurie, G. I., Bautista Mendoza, G. R., Alajbeg, I., Pejda, S, Vuletic, L.,…Konttinen, Y. T. (2011). Efficacy and safety of an intraoral electrostimulation device for xerostomia relief. *Arthritis & Rheumatism, 63*(1), 180-190. doi: 10.1002/art.27766

Tamowska, C., Amernik, K., Matyia, G., Brzsko, I., Grzelec, H., & Burak, M. (2004). Fixation of the crico-arytenoid joints in rheumatoid arthritis-preliminary report. *Otolaryngologia Polska, 58*(4), 843-849. Retrieved from http://www.elsevier.com/journals/otolaryngologia-polska/0030-6657

Tanner, K., Roy, N., Merrill, R. M., Sauder, C., Houtz, D. R., & Smith, M. E. (2011). Spasmodic dysphonia: Onset, course, socioemotional effects, and treatment response. *Annals of Otology, Rhinology & Laryngology, 120*(7), 465-473. Retrieved from http://www.annals.com/

Vergnenegre, A., Pugnere, N., Antonini, M. T., Arnaud, M., Melloni, B., Treves, R., & Bonnaud, F. (1997). Airway obstruction and rheumatoid arthritis. *The European Respiratory Journal*, *10*, 1072-1078. Retrieved from http://erj.ersjournals.com/

Vertigan, A. E., Gibson, P. G., Theodoros D. G., & Winkworth A. L. (2008). The role of sensory dysfunction in the development of voice disorders, chronic cough and paradoxical vocal fold movement. *International Journal of Speech Language Pathology, 10*(4), 231-44. doi:10.1080/17549500801932089

Webb, J., & Payne, W. H. (1972). Rheumatoid nodules of the vocal folds. *Annals of the Rheumatic Diseases, 31*, 122-125. Retrieved from http://ard.bmj.com/

Weber, B., Portnoy, J. E., Castellanos, A., Hawkshaw, M. J., Lurie, D., Katz, P. O., & Sataloff, R. T. (2014). Efficacy of anti-reflux surgery on refractory laryngopharyngeal reflux disease in professional voice users: A pilot study. *Journal of Voice, 1997*(13), 256-7. doi:10.1016/j.jvoice.2013.12.009

Wilson, D. (2006). Rheumatoid factors in patients with rheumatoid arthritis. *Canadian Family Physician, 52*(2), 180-181. Retrieved from http://www.cfp.ca/

Wise, J. L., & Murray, J. A. (2006). Oral, pharyngeal, and esophageal motility disorders in systemic diseases. *GI Motility online*. doi:10.1038/gimo40

Woo, P., Mendelsohn, J., & Humphrey, D. (1995). Rheumatoid nodules of the larynx. *Otolaryngology Head and Neck Surgery, 113*(1), 147–150. Retrieved from http://oto.sagepub.com/